



# EPA-UNEPSA SCIENTIFIC ACTIVITY (2012-2015)

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EPA-UNEPSA, the  
European Paediatric  
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European Paediatric  
Societies and  
Associations*

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Graphics and Layout: ZEROUNO by Alessandro Tellini

info@zerounoprojects.it, Via Croce di Sarna, 57 52010 Croce di Sarna (AR), Italy

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EPA-UNEPSA Main Office, Allta. Center, Zimmerstraße 69, D-10117, Berlin, Germany

## INTRODUCTION

*The European Paediatric Association-Union of National Paediatric Societies and Associations (EPA-UNEPSA) complies with the strategy of building bridges between and among medical and non-medical experts.*

*The aim of EPA is to educate without being limited by boundaries, across country borders, while respecting national idiosyncrasies.*

*In the past 6 years EPA-UNEPSA has brought 50 national paediatric associations and societies closer together to stimulate “learning across borders” and to start the debate on different issues of child health care ranging from psychological to medical, legal and economic topics.*

*Furthermore EPA-UNEPSA expanded on planning, performing and publishing studies on child health care services in Europe.*

*Last but not least EPA attracted not only paediatricians but also other experts in child health care who were willing to be actively involved in projects aiming at improving child health care on a European level.*

*The aims of the European Paediatric Association are to improve the health of children and young people in Europe, and to improve the quality of health care services for children and their families in Europe.*

*The articles which are included in this e-book deal with a great variety of topics reflecting current discussions and controversies, idiosyncrasies and standards, gaps and bridges as well as challenges and achievements.*

*With respect to the enormous benefit of successful communication between professionals we have chosen to make most of our previous publications available to as many paediatricians as possible.*

*EPA has to broaden its intellectual basis by creating a multidisciplinary society to avoid fragmentation of paediatrics, and to allow to tackle the legal, economic and organisational challenges of child health care in Europe, and last but not least to put the children and young people into the centre of EPA activities.*

*Enjoy reading the articles and please do not hesitate to contact the EPA-UNEPSA Scientific Advisory Board by sending your questions and comments to the articles. Our motto is “starting the debate”.*

**Leyla Namazova-Baranova**

**Massimo Pettoello-Mantovani**

**Jochen H.H. Ehrich**

*EPA-UNEPSA Executive Committee*

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EPA-UNEPSA Scientific Advisory Board:

Höhenblick 13, 38104 Braunschweig, Germany – [scientificadvisoryboard@epa-unepresa.org](mailto:scientificadvisoryboard@epa-unepresa.org)

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# Thirty-Six Years of the European Paediatric Association–Union of National European Paediatric Societies and Associations (EPA-UNEPSA)

Jochen H. H. Ehrich<sup>1,2</sup>, Massimo Pettoello-Mantovani<sup>1,3</sup>, and Armido Rubino<sup>1,4,5</sup>

Managing the health care of infants, children, and adolescents in Europe requires balancing clinical aims, research findings, and socioeconomic goals within an international environment characterized by cultural and economic complexity and large disparity in availability, affordability, and accessibility of pediatric care. Since 1976, the European Paediatric Association (EPA), formerly Union of National European Paediatric Societies and Associations (UNEPSA), has been trying to establish this balance, involving almost two generations of European pediatricians. This report explores how EPA-UNEPSA has gone through evolutionary periods and describes the founding generation of pioneers, as well as the formulation of clinical aims. This is the first of several reports examining the highlights of the association and its congresses (EUROPAEDIATRICALS), including the research activities according to each stage of development.

During the international conference on the nutrition of infants and children in August 1975 in Montreux, Switzerland, 11 delegates of different European national pediatric societies decided to found UNEPSA. On June 20, 1976, the official foundation of UNEPSA took place in the St Sophia Children's Hospital in Rotterdam, the Netherlands, and the constitution was ratified by 18 representatives of national pediatric societies in Europe (Table I).

The first 10-year period of EPA-UNEPSA was an era of tremendous efficiency, with friendly interaction between the active members to promote communication among pediatric centers in Europe. EPA-UNEPSA continuously aimed to enhance primary, secondary, and tertiary pediatric care of all European children. Achieving the goal, EPA-UNEPSA relied on the principal challenges of international social responsibility with respect to children by initiating a strategy and basis for collection of demographic data, communication, confidentiality, cooperation, and consensus of all decision makers. In 1987, Bertil Lindquist and Klaus Betke gave a critical review of the achievements of UNEPSA during the first 10 years.<sup>1</sup> The two main achievements were: (1) the integration of European pediatrics into worldwide pediatrics as represented by the International Pediatric Association; and (2) the stimulation of professional contact between pediatricians from Eastern and Western Europe. The merit of the UNEPSA pioneers was that they created the basis for future communication and cooperation among European pediatricians.

During the next 15 years, the political situation in Eastern Europe changed dramatically and the Europe of 53 nations started a new chapter. The first generation of members of EPA-UNEPSA observed with great concern the fact that the rapid expansion of diagnostic and therapeutic facilities in Western European countries was not followed by a similar development in Eastern Europe, thus widening the gap of diversity of child health care in Europe with >250 million children aged <18 years.

In the 1990s, it became clear that, due to the expansion of scientific knowledge, technology, and specialization, pediatrics was running the risk of being fragmented into—and replaced by—an increasing number of subspecialties. This form of evolution would have gone against the rights of children and adolescents to receive care as individuals, rather than as organs or tissues, with a holistic approach. Therefore, after seeing the extraordinary and positive results of subspecialties in their role of advancing and promoting child health, EPA-UNEPSA particularly focused its attention on the aim of maintaining a strong general pediatrics and interculturally supporting the general pediatricians in their role of providing primary and secondary care to children and adolescents.

In the most recent 10-year period, EPA-UNEPSA focused on adapting to the new era in pediatrics by establishing continuous communication with those societies and associations offering health care to children (eg, general practitioners, family physicians, specialists, nurses, psychologists, parents' organizations) and inviting them to the EUROPAEDIATRICALS congresses for active exchanges of ideas.

EPA-UNEPSA also expanded to study diversity of pediatric health care in Europe and provided information on the provision of adequate, affordable, accessible, available diagnostic, and therapeutic care, as well as equity, efficacy, and efficiency of pediatric care for all pediatricians in Europe.<sup>2,3</sup> 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, as well as the use of high-tech medicine. EPA-UNEPSA aims at providing a panel for discussions for pediatricians to provide evidence-based practice guidelines that are based on scientific findings. However, EPA-UNEPSA is well aware that their national application may depend on country-specific priorities influencing

EPA	European Paediatric Association
UNEPSA	Union of National European Paediatric Societies and Associations

From the <sup>1</sup>European Paediatric Association–Union of National European Paediatric Societies and Associations, Berlin, Germany; Departments of <sup>2</sup>Pediatrics and <sup>3</sup>Medicine, Children's Hospital, Hannover Medical School, Hannover, Germany; <sup>4</sup>Institute of Pediatrics, University of Foggia, Foggia, Italy; and <sup>5</sup>Department of Paediatrics, University of Naples Frederick II, Naples, Italy

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**Table I.** Presidents and secretary generals of EPA-UNEPSA

	Term of office	Country
<b>President</b>		
Bertil Lindquist	1976-1982	Sweden
Angel Ballabriga	1983-1986	Spain
Jean Rey	1987-1990	France
Timothy Chambers	1991-1994	United Kingdom
Armido Rubino	1995-1997	Italy
Jochen H.H. Ehrich	1998-2000	Germany
Jan Janda	2001-2004	Czech Republic
Armido Rubino	2005-2007	Italy
Andreas Konstantopoulos	2008-present	Greece
<b>Secretary general</b>		
Klaus Betke	1976-1985	Germany
Eberhard Schmidt	1986-1993	Germany
Jochen H.H. Ehrich	1994-1997	Germany
Manuel Katz	1998-2001	Israel
David Branski	2002-2009	Israel
Massimo Pettoello-Mantovani	2010-present	Italy

appropriate use and updating. Last, but not least, EPA-UNEPSA and other organizations (eg, International Pediatric Association, European Academy of Paediatrics) have reached a high level of international communication, cooperation, and consensus to further the pediatric care of children.

In summary, in the 36 years of the existence of EPA-UNEPSA, it has become clear that the diversity of pediatric

**Table II.** Selection of congresses organized by EPA-UNEPSA

Congress	Organizer	Date	Location
1st EUROPAEDIATRICS 2000	Armido Rubino	March 18-21, 2000	Rome
2nd EUROPAEDIATRICS 2003	Manuel Katz and Jan Janda	October 19-23, 2003	Prague
3rd EUROPAEDIATRICS 2008	Mehmet Vural	June 14-17, 2008	Istanbul
4th EUROPAEDIATRICS 2009	Alexander A. Baranov	July 3-6, 2009	Moscow
5th EUROPAEDIATRICS 2011	Wilhelm Kaulfersch	June 23-26, 2011	Vienna
6th EUROPAEDIATRICS 2013	Terence Stephenson	June 5-8, 2013	Glasgow

**Table III.** Member countries of EPA-UNEPSA (1976-2010, in 2011 Armenia became the 37th member)

Albania	Germany	Poland
Austria	Great Britain	Portugal
Belgium	Greece	Romania
Bosnia-Herzegowina	Hungary	Russia
Bulgaria	Ireland	Serbia
Croatia	Israel	Spain
Cyprus	Italy	Sweden
Czech Republic	Latvia	Switzerland
Denmark	Lithuania	Slovakia
Estonia	Luxemburg	Slovenia
Finland	Macedonia	Turkey
France	Netherlands	Ukraine

care among 53 different countries in Europe is immense. Annual meetings with national pediatric presidents focus on the most urgent problems of pediatric health care. EUROPAEDIATRICS became the tri-annual congress for all general pediatricians and pediatric subspecialists in Europe (**Table II**). The main research activities of EPA-UNEPSA concentrate on identifying the demography of primary, secondary, and tertiary care pediatrics in Europe, with the objective of promoting strong advocacy and political intervention in order to ensure the delivery of high-quality health care to children throughout Europe. EPA-UNEPSA is an active pediatric association representing more than three-quarters of all European countries (**Table III**). After 36 years, it is still expanding and improving both medical care of all children and cooperation of their caretakers in Europe. ■

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## European Challenges: Cross-Border Care for Children

Ulrike Salzer-Muhar, MD<sup>1</sup>, Arnold Pollak, MD<sup>1</sup>, Christoph Aufricht, MD<sup>1</sup>, Jochen Ehrich, MD<sup>2,3</sup>, and Simon Lenton, FRCPC<sup>4</sup>

Europe has seen a 60-year era of postwar peace, wealth, social justice, and ecological awareness. This prosperity and resultant improved health has not been experienced equitably across all population groups, however. Indeed, inequalities within and between nations have increased over this time, and that trend shows no sign of changing. The banking crisis and the entry into a period of austerity are likely to accelerate the trends toward greater inequities. Children and young people will be particularly adversely affected as poverty, unemployment, reduced benefits, and cuts in public services are experienced. The unemployment rates among young people have already reached alarming levels in the countries most burdened by excessive national debt. An examination of life course epidemiology suggests that future investments should be made in childhood to prevent morbidity in adulthood, but the demographic shift toward the elderly population as individuals live longer is creating demands on health services that are outstripping the available resources. This will eventually precipitate a debate on where resources are best invested. The answer to this question will depend not only on good evidence and econometric studies, but also on cultural values and attitudes about social solidarity.

Currently there are considerable variations in the access to, and quality of, specialized pediatric services across Europe, with the starkest difference between Eastern European and Western European nations. This is leading to increased numbers of families seeking highly specialized care in countries outside their own. Despite an awareness of the problem by the European Union (EU) member states, how national governments should best respond to complex issues regarding cross-border healthcare remains unclear.<sup>1</sup> There is also a lack of Euregios offering cooperative healthcare in regions of neighboring countries.<sup>2</sup>

There is a paucity of demographic data on pediatric cross-border health care in Europe. The aim of the European Paediatric Association is to analyze the current situation to provide the necessary evidence to improve future priority setting and decision making. This will require a degree of cooperation, collaboration, and coherence of an approach on a pan-European basis if we are to understand how different health systems create the outcomes that they achieve for their children and young people. The European Paediatric Association has identified the need for professional pediatric socie-

ties to establish best practice clinical pathways, standards, and measures for cross-border pediatric care.

This report provides a review on concerns and options around cross-border pediatric care based on the findings of the “Bridges for Combating Health Inequalities in Life-Threatening Diseases (CHILD)” conference held on November 17-18, 2011, in Vienna, Austria, supported by a EU grant provided by the Executive Agency for Health and Consumers within the frame of the second Health Program (agreement no. 2010 42 04; [www.bridgesforchild.eu](http://www.bridgesforchild.eu)). The purpose of the conference was to examine the options for improving current practice and policy of cross-border care in Europe for children requiring specialist care for life-threatening diseases of the heart, lungs, liver, and kidneys.

Europe is divided into 46 countries (plus 7 small states, including the Vatican and Monaco), with a total of 184 border regions with large populations. Two islands of the 46 countries have no border region, 37 countries have between 1 and 6 border regions, and 7 countries having 7 or 8 (mode: 4). Seven the 46 countries have fewer than 2 million inhabitants and another 7 countries have a population of 2-4 million. Therefore, one-quarter of European countries may be too small to offer highly specialized health care within their national health systems to their small number of children with rare and complex diseases. Thus, for example, in countries like Macedonia, all children needing open-heart interventions for congenital heart malformations are sent to Sofia, Bulgaria, for surgery.

The borders are not only geographical, but also cultural where healthcare systems interface. Understanding the diversity of child healthcare means that each individual and nation is unique and recognizes and works with these individual and national differences. These can be along the dimensions of ethnicity, culture, socioeconomic status, religious beliefs, political beliefs, and other ideologies. These differences and their influences on cross-border care should be explored in a safe, positive, and nurturing environment. The conference site of Vienna was chosen to host Bridges for CHILD because the Medical University of Vienna is located in the center of Europe, where east, west, north, and south naturally meet. Eighty-eight participants, including pediatric subspecialists

CHILD	Combating Health Inequalities in Life Threatening Diseases
EU	European Union

From the <sup>1</sup>Department of Pediatrics and Adolescent Medicine, Medical University of Vienna, Vienna, Austria; <sup>2</sup>European Paediatric Association–Union of National European Paediatric Societies and Associations, Berlin, Germany; <sup>3</sup>Children’s Hospital, Hannover Medical School, Hannover, Germany; and <sup>4</sup>Child Health Department, Bath, United Kingdom

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**Table I.** Arguments for and against developing a more rational system on European cross-border transplant care for children

## Arguments for a more rational system

- Children have the right to high-quality health care regardless of cultural background or ability to pay (article 24, United Nations Convention on the Rights of the Child).
- The current system is not efficient, effective, or equitable, and, in times of economic austerity, there is a greater moral obligation to use limited resources wisely.
- Increasing the number of children accessing specialist centers potentially improves the quality of care provided in those centers as their confidence improves with increasing numbers.
- Addressing the issue of the threshold for accessing specialist care should improve decision making along the whole pathway of care. This has the potential to improve the quality of primary and secondary care as well.
- The purpose of the EU and of the Council of Europe is to create social solidarity based on human rights, democracy, and the rule of law.

## Arguments against a more rational system

- Specialist care, especially interventional specialist care, such as transplantation, is expensive. This may be unaffordable for resource-poor nations.
- The opportunity costs for others may be unacceptable for the society (eg, 1000€ could save more lives if spent in different ways).
- Posttransplantation services are unlikely to be available in resource-poor nations.
- A higher priority in many nations is the development of effective and responsive palliative care services.
- There seems to have been a lack of political willingness to tackle this difficult issue in the past, the argument being that each nation should resolve its own problems without taking a pan-European approach.

from 20 European countries, as well as parents of sick children, health insurance experts, politicians, representatives of nongovernmental organizations, and medical students, attended the conference. The 2-day conference included invited lectures and 9 round-table sessions. The individual commitment of all participants and the multidisciplinary lineup, combined with the roundtable format, contributed to the conference's success.

Many European children with severe conditions are not receiving high-quality care; therefore, their experience and outcomes of services are poor. Poor-quality care generally costs more in the long term, and the current system is ineffective, inefficient, or inequitable in many countries. This is particularly true for children living in resource-poor nations, generally those toward the east of Europe, which have less-developed services. The problem is compounded by the difficulties in accessing cross-border care, which include social, political, and financial dimensions. From the perspective of the European pediatric specialist centers in the better-

developed nations, they are receiving multiple requests every week, often without adequate information to enable appropriate decision making, which reflects the quality of care in the country of origin. If one request for specialist care is turned down, further requests to other specialist centers are made, and the whole process is hugely time-consuming and inefficient. Arguments for and against Europe-wide structured cross-border care are listed in [Table I](#). Additional factors involved are described in [Table II](#).

The intention of Bridges for CHILD is to create a system that improves quality throughout each child's pathway from prevention through identification/recognition and comprehensive assessment of both child and family to improve access to a range of effective interventions, including specialist care for both severe and rare conditions. Although the focus of the conference was on high-tech surgery and transplantation for life-threatening conditions, many recognized that the quality of care throughout the child's life was equally important and could significantly delay the need for

**Table II.** Additional factors that need to be considered

- Access to specialist care must not be seen in isolation from the care the child received before and after access to specialist care. Thus, improving the quality of care before and after specialist interventions is an equal priority.
- Current systems for accessing specialist care are often highly bureaucratic, time-consuming, and illogical and do not facilitate "the right care, for the right child, by the right people, in the right place, at the right time."
- Access to specialist care in Europe needs to be seen as a "whole systems" issue. Changing whole systems requires agreement among all of the stakeholders, including users of services, their political representatives, financial systems (whether public, insurance-based, or private), health professionals, and other agencies that contribute.
- In all social systems, there is an element of financial risk pooling meaning everyone contributes a little to benefit should an individual catastrophe occur. The question is how far the borders should be stretched for risk pooling for health conditions: regional, national, or international?
- The EU offers subsidies to farmers and other industries, but generally not within healthcare.
- The development of specialist centers within Europe needs to be limited so that the current centers have sufficient capacity to maintain and expand their competence.
- Many specialist services are codependent on one another, and, thus, decisions made for one specialist service must be seen in the context of developments for interrelated specialist services. This may require a rationalization of the location of specialist services across Europe.
- Horizon scanning. As medicine and technology improve, current interventions may be substituted with less-invasive future procedures. Developments in stem cell technology, gene therapy, and nanotechnologies need to be considered so that decisions taken today are compatible with the likely future developments.
- Payment methods for specialist care should be reviewed to adequately remunerate specialist centers undertaking the work. Often children with rare conditions have multiple comorbidities that influence the interventions and outcomes required. Children from other countries require translating services, and their families often need help with transportation and accommodation costs. Care for other children in the family also needs to be considered.
- Improving the quality of care for children requiring specialist care also requires improved transparency about what centers offer what services and the quality and outcomes that they achieve.

**Table III. Urgent actions envisaged during the roundtable sessions of “Bridges for CHILD”**

How to treat children with congenital heart disease under adverse economic conditions?

- A patient database in the Pediatric Cardiac Center of Prishtina University, Republic of Kosovo, will be set up.
- An educational twinning project on decision making in CHILD scenarios between Prishtina University and Vienna University will be established before the end of 2012.

How to achieve accountability in new cardiology centers?

- Parents' desire for cross-border training of local cardiac experts and for further public support of the European Congenital Heart Disease Organization will be reported to the Association of European Paediatric and Congenital Cardiology.
- National parents' organizations will stimulate medical associations in their countries to establish basic guidelines for standard treatment of children with congenital heart disease and other life-threatening diseases.

What is needed to ensure optimal care of children and adolescents before and after cross-border lung transplantation?

- The Vienna lung transplant center will invite insurance and health care authorities of Eastern European countries to a meeting, and it will also apply for grants from the European Respiratory Society and the Cystic Fibrosis Foundation.
- The issue of cross-border lung transplantation will be included into the programs and agendas of future national meetings in Hungary and Austria.

How to organize care pathways in solid organ/stem cell transplantation?

- A team will be put together to define the relevant variables for analysis of the current status and, thereafter, to identify specialists who could become members of a Pediatric Cross-Border Transplant Task Force.
- A task force on cross border pathways for children with life-threatening kidney diseases will be proposed to the European Society for Paediatric Nephrology.

What can universities contribute to the reduction of health care inequalities in European child healthcare?

- A task force for a telemedicine model on decision making in CHILD scenarios will be set up.

How to structure care pathways for life-threatening/life-limiting diseases in local and cross-border health care?

- The potential will be explored for a single clearing house for requests for solid organ transplants and advocates developing standards for centers providing solid organ transplants.

How to transform the directive on patients' rights in cross-border health care into reality: economic gradients, medical indications, and codes of conduct?

- Those medical establishments involved in cross-border pediatric tertiary care should set up guidelines for acceptance and nonacceptance of patients from other countries.

organ replacement therapy if all of the decisions had been made at the right time. There will be a spectrum of options, but 4 options were presented as a starting point: (1) current trajectory, increasing the numbers of children “randomly” receiving specialist care as public awareness of the options available become more widely known; (2) partnership programs, with large specialized centers in Europe “partnering” with less well-resourced nations to provide education and training, outreach services, and specialist interventions and after care determined by respective governments/insurance/health systems; (3) clearing house, with requests for specialist care considered by a panel of experts who collectively decide on a pan-European basis whether the child can benefit from specialist care and determine to which center the child is referred; and (4) designated centers, with a limited number of comprehensive centers of excellence designated and funded by the EU to undertake specific interventions for children meeting agreed-upon criteria.

In summary, the participants of the CHILD conference agreed that European pediatricians should analyze and describe the present situation, and several proposals for

new initiatives were made (**Table III**). The CHILD Task Force members will be expected to present results at the proposed second Bridges for CHILD conference to be held in 2014 in Vienna. Clinicians should initiate the process of reforming health services for children and families, and should start the process by being open about where the systems are not working and the reasons for these deficiencies, and reaching consensus within pediatric subspecialty services. In the longer term, to be politically credible and sustainable, pediatricians need to form alliances with patient organizations, health service managers, and the organizations that plan and finance services. ■

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## Health services for children in western Europe

Ingrid Wolfe, Matthew Thompson, Peter Gill, Giorgio Tamburlini, Mitch Blair, Ann van den Bruel, Jochen Ehrich, Massimo Pettoello-Mantovani, Staffan Janson, Marina Karanikolos, Martin McKee

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This is the fourth in a **Series** of seven papers about health in Europe

European Centre on Health of Societies in Transition (I Wolfe MSc, M Karanikolos MSc, Prof M McKee MD), and European Observatory on Health Systems and Policies (M Karanikolos, Prof M McKee), London School of Hygiene & Tropical Medicine, London, UK; Department of Primary Care Health Sciences, University of Oxford, Oxford, UK (M Thompson, P Gill BMSc, A van den Bruel PhD); Centro per la Salute del Bambino, Trieste, Italy (G Tamburlini PhD); Division of

Western European health systems are not keeping pace with changes in child health needs. Non-communicable diseases are increasingly common causes of childhood illness and death. Countries are responding to changing needs by adapting child health services in different ways and useful insights can be gained through comparison, especially because some have better outcomes, or have made more progress, than others. Although overall child health has improved throughout Europe, wide inequities remain. Health services and social and cultural determinants contribute to differences in health outcomes. Improvement of child health and reduction of suffering are achievable goals. Development of systems more responsive to evolving child health needs is likely to necessitate reconfiguring of health services as part of a whole-systems approach to improvement of health. Chronic care services and first-contact care systems are important aspects. The Swedish and Dutch experiences of development of integrated systems emphasise the importance of supportive policies backed by adequate funding. France, the UK, Italy, and Germany offer further insights into chronic care services in different health systems. First-contact care models and the outcomes they deliver are highly variable. Comparisons between systems are challenging. Important issues emerging include the organisation of first-contact models, professional training, arrangements for provision of out-of-hours services, and task-sharing between doctors and nurses. Flexible first-contact models in which child health professionals work closely together could offer a way to balance the need to provide expertise with ready access. Strategies to improve child health and health services in Europe necessitate a whole-systems approach in three interdependent systems—practice (chronic care models, first-contact care, competency standards for child health professionals), plans (child health indicator sets, reliable systems for capture and analysis of data, scale-up of child health research, anticipation of future child health needs), and policy (translation of high-level goals into actionable policies, open and transparent accountability structures, political commitment to delivery of improvements in child health and equity throughout Europe).

### Introduction

The health care needs of Europe's children are changing as a result of variations in the diseases, disabilities, and social factors that affect their lives. Infectious diseases have become easier to prevent or cure, and non-communicable diseases increasingly dominate paediatric practice. Health services have not adapted sufficiently to these changes and, in some instances, fail to deliver high-quality care. European health systems need to develop new models of care to meet children's current and evolving health needs. Although rare disorders, such as childhood cancers, cardiac anomalies, and some neonatal problems need highly specialised care (provided in selected centres), common problems—eg, asthma, diabetes, behavioural disorders, mental health problems—can be cared for in the community to enable children and their families to live as normally as possible. Development of better systems will probably need reconfiguring of services across the interfaces between hospitals, primary care, and public health. However, these changes are very difficult to achieve because the boundaries between specialties and health-care delivery organisations are often points of contention in both health-care professionals and policy makers. Although the 15 pre-2004 countries of the European Union (EU15) face common challenges, they are responding in different ways, which show their differing histories, organisational structures, financing systems,

### Key messages

- Child health systems in Europe are not adapting sufficiently to children's evolving health needs, leading to avoidable deaths, suboptimum outcomes, and inefficient use of health services.
- If all the 15 pre-2004 countries of the European Union had child mortality closely similar to that of Sweden (the country with the best rate), more than 6000 deaths per year could be prevented.
- Chronic care models for children are needed to improve care and outcomes for non-communicable diseases, and ensure better quality of life for children and families. Several countries have made progress in development of chronic care services, and offer lessons for others.
- First-contact care services and outcomes for children in Europe are highly variable. Flexible models, with teams of primary care professionals trained in child health working closely together, might offer a way to balance expertise with access.
- Child-health indicator sets with reliable and uniform systems for data collection would ease efforts to monitor needs and improve services.
- Awareness of the importance of investment in the earliest years is growing. Individual countries and European-Union-wide organisations should strengthen investment in child health and health services research.
- Politicians and policy makers should do more to translate high-level goals for child health into implemented policies with accountability structures to ensure delivery. Investment in social protection policies for the earliest years and the most vulnerable children will improve health, reduce inequities, and accumulate advantages throughout the life course.

and professional roles. These variations provide many opportunities to learn from others' experiences, especially because some countries are achieving much better outcomes than are others.<sup>1</sup>

In this paper, we review child health and the determinants of child health in the EU15 and evidence for how well health-care needs are met by services. We will then examine different approaches to important aspects of paediatric practice—namely, services for children with chronic disorders and first-contact care—because, together with public health and social determinants, health services are essential to improve children's health. These variations between countries provide learning opportunities. We focus on countries that have had better outcomes than others, because such countries show what can be achieved, and on countries that have assessed attempts to reconfigure services to meet needs, because they can show how to achieve changes. Finally, we set out a plan to improve the health of Europe's children.

### Child health in Europe

Child survival has improved greatly in the past three decades in all EU15 countries as a result of improvements in public health, health care, and wider societal factors (figure 1; appendix). A concomitant shift in the distribution of causes of childhood deaths has occurred (figure 2)—specifically, deaths from infections and respiratory causes have fallen while the proportion attributable to non-communicable diseases has risen. In 2009–10, the most frequent causes of death in children aged 1–14 years in the EU15 were injury and poisoning, cancer, and “other” (largely congenital anomalies and neurological disorders).<sup>2</sup> Morbidity in children is also dominated by non-communicable diseases, accounting for 79% of disability-adjusted life-years lost (figure 3). Of the non-communicable diseases, the most common three causes of morbidity are neuropsychiatric disorders (mainly depression), congenital abnormalities, musculoskeletal disorders (lower-back pain), and respiratory diseases (mainly asthma).<sup>3</sup>

These data for morbidity and mortality in Europe conceal wide variations in child health between and within countries. Striking inequities can be noted in children's life chances and health outcomes, resulting from a complex interaction of cultural, social, and economic forces, including differential risk exposure and access to high-quality health care.<sup>4</sup> Health status and a country's wealth (as measured by gross domestic product) are clearly associated, and this association is likely to be related to access to resources and equity of distribution (appendix).

If all countries in the EU15 could reduce their child mortality to that of Sweden (the best-performing country), more than 6000 excess deaths could have been prevented in 2010 (table). This goal is achievable. Many aspects of child health are affected by government policies, especially policies that affect the distribution of resources, employment, housing, education, and health care. Thus,

countries with high spending on social protection for families generally have low rates of child death (appendix).

The extent of child poverty and inequality in Europe is not always realised. In Sweden, 1·3% of children live in deprivation, whereas in Portugal 27·4% of children live in households that cannot afford to eat three meals per day.<sup>5</sup> In view of the lag in availability of data, the situation is probably even worse because of the financial crisis.<sup>6</sup> Aggregate figures for whole countries conceal socioeconomic inequalities that particularly affect children from ethnic minorities. The Roma people are Europe's largest minority population, and continue to be subject to discrimination in many parts of Europe; child health outcomes, such as preterm birth, incidence of communicable diseases, and death, are often much worse in the Roma than in the majority population.<sup>7,8</sup> Other

Paediatrics, Imperial College, London, UK (Prof M Blair MSc); Medizinische Hochschule, Hannover, Hanover, Germany (Prof J Ehrlich MD); School of Medicine, University of Foggia, Foggia, Italy (Prof M Pettoello-Mantovani PhD); and Centre for Public Health Research, Karlstad University, Karlstad, Sweden (Prof S Janson PhD)

Correspondence to: Dr Ingrid Wolfe, London School of Hygiene & Tropical Medicine, 15–17 Tavistock Place, London WC1H 9SH, UK  
ingrid.wolfe@lshtm.ac.uk

See Online for appendix

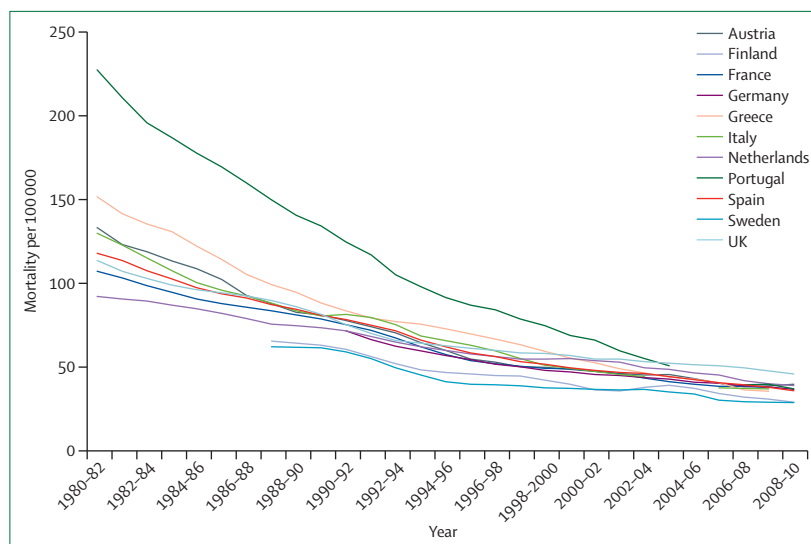


Figure 1: Trends in mortality in children aged 0–14 years in 11 European Union countries, 1980–2010  
Source: WHO Mortality Database, 2012.<sup>2</sup> Data are directly standardised rates.

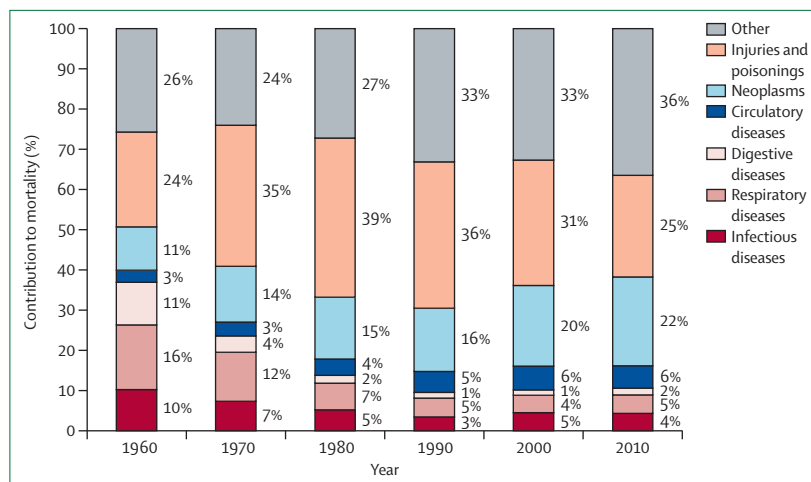
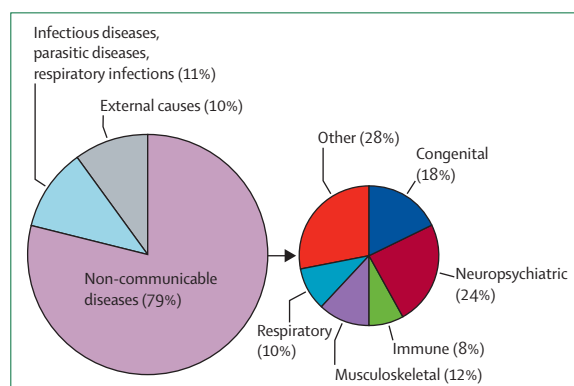


Figure 2: Shifting relative causes of mortality in children aged 1–14 years in the 15 pre-2004 countries of the European Union, 1960–2010  
Source: WHO Mortality Database, 2012.<sup>2</sup>



**Figure 3: DALYs in children aged 0–14 years in western Europe, 2004**

Source: Institute for Health Metrics and Evaluation.<sup>3</sup> Data show proportion of DALYs attributed to disease groups for children aged 0–14 years. Data exclude perinatal and maternal DALYs. DALYs=disability-adjusted life-years.

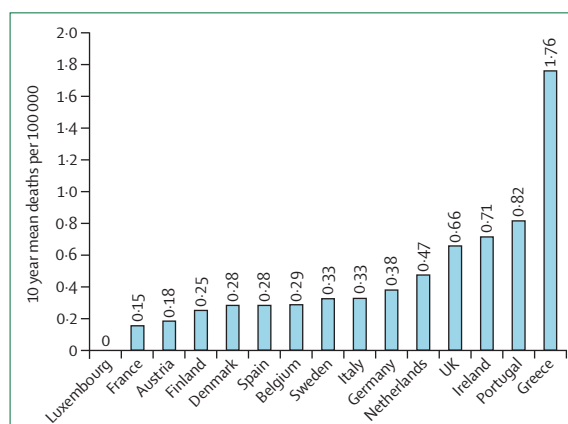
	Mortality (directly standardised rate)	Yearly excess deaths compared with Sweden
Sweden	29.27	0
Luxembourg	26.50	0
Finland	30.27	9
Spain	37.40	545
Greece	37.86	135
Germany	37.88	815
Italy	38.07	683
France	38.25	962
Austria	39.09	106
Ireland	39.78	98
Netherlands	40.66	292
Portugal	40.73	176
Denmark	42.69	121
UK	47.73	1951
Belgium	47.77	304

Source: WHO Mortality Database, 2012.<sup>7</sup> Directly standardised rate data show all-cause mortality per 100 000 children aged 0–14 years and are 5 year means for 2006–10, except for France and Luxembourg (2005–09), Denmark (2002–06), Belgium (1998–99; 2004–06), Italy (2003; 2006–09); and Portugal (2003; 2007–10). Data for excess deaths are absolute numbers. An estimated 6198 deaths would have been avoided if the child mortality rate across the 15 pre-2004 countries of the European Union was the same as that in Sweden.

**Table: Child mortality rates in the 15 pre-2004 countries of the European Union and excess child deaths compared with Sweden**

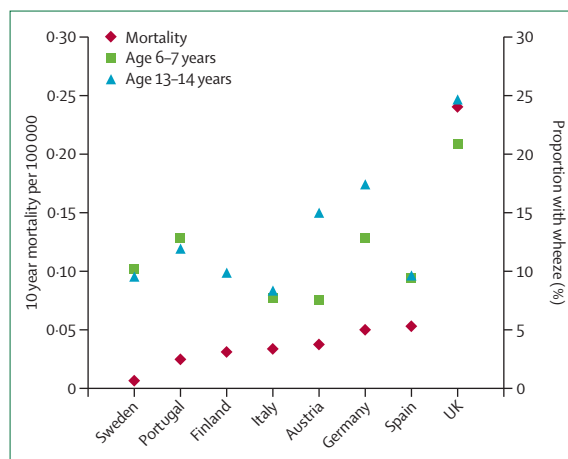
children at particular risk are those in migrant families who are not legally entitled to live in their countries of residence; such children face additional discrimination in many countries. Failure to enact policies that support disadvantaged children and their families, particularly in their earliest years, has long-lasting consequences, including missed opportunities to interrupt the accumulation of disadvantage through the life course and prevent transmission to the next generation.<sup>4</sup>

Many specific measures can be taken to protect children—a fact shown by data for mortality from injuries and violence. External causes of death are much



**Figure 4: Deaths from pneumonia in children aged 0–14 years in the 15 pre-2004 countries of the European Union**

Source: WHO European Mortality Database, 2012.<sup>13</sup> Data are directly standardised rates. 10 years means are for 2000–10, except for data for Belgium (2004–06); Denmark (2000–06); France, Greece, and Italy (2000–09); and Portugal (2000–04 and 2007–10).



**Figure 5: Asthma mortality rate in children aged 0–14 years, and proportion aged 6–7 and 13–14 years with wheeze, in eight western European countries**

Source: WHO European Mortality Database,<sup>13</sup> 2012, and Anderson and Colleagues.<sup>14</sup> Data are for 2000–10, except for data for Belgium (2004–06); Denmark (2000–06); France, Greece, and Italy (2000–09); and Portugal (2000–04; 2007–10). Mortality data are directly standardised rates.

more common in children in poor families and in poor countries than in children in richer families and in richer countries.<sup>9</sup> Northern European countries—eg, Sweden and the Netherlands—have achieved sustained reductions in child deaths from road traffic injuries through legislation and measures directed at reduction of traffic speed, separation of vehicles from other road users, and mandating of safety equipment (such as child restraints). France reduced rates of childhood drowning by legislating pool safety.<sup>10</sup>

### Meeting health needs

Health services for children, as an important and modifiable determinant of health, are the main focus of

this paper. The rate of deaths from disorders that are amenable to health care is a measure of effectiveness.<sup>11</sup> Two common illnesses show variability in outcomes and thereby scope for improvement. Pneumonia is the most common serious bacterial infection in children presenting in primary care,<sup>12</sup> and deaths in childhood from this disease should be avoidable in most cases. However, death rates vary substantially within the EU15, from 0 to 1.76 per 100 000 (figure 4). Mortality from asthma, a chronic disease common in childhood, varies substantially between countries, even after adjustment for the incidence of wheeze as a proxy indicator for prevalence of asthma (figure 5). However, mortality is not the only consideration; research in several countries has shown that as many as two-thirds of hospital admissions for asthma in children could be avoided with better preventive care, including asthma action plans, improved asthma education, and reduction of risk factors (eg, parental smoking).<sup>15,16</sup> National differences in mortality from these health-care-amenable illnesses suggest that scope for improvement of management and outcomes is great.

### Learning from experience in delivery of care

European health systems have been slow to adapt to the changing patterns of childhood morbidity and mortality. Although there is a broad consensus that many non-acute health services could shift from hospital-based to community-based delivery, thus improving access and responsiveness and reducing costs, most countries have yet to do so. Such changes, however, should not compromise the provision of highly specialised and acute emergency care. The challenge is to find innovative ways to address and reach these complex and potentially competing goals. We reviewed selected aspects of child health services that might help to differentiate countries that are doing well from those that are doing less well (panel 1). We draw attention to learning points from countries with good outcomes or from those that have made progress in, and assessed, health service reform. We do not discuss highly specialised aspects of care because such services are provided in broadly similar ways throughout the EU15, and the health-care professionals who work in such specialties frequently collaborate through international networks.

### Care of chronic disorders

Care of chronic disorders in adults has been high on the policy agenda in many European countries for the past decade, exemplified by the widespread use of elements of the chronic care model.<sup>18</sup> The research informing chronic care has shown that several factors are consistently associated with successful health-care delivery for adults—namely, shared practice with common guidelines; conducive organisational arrangements, such as colocation of health and social services; information sharing; supportive financial processes; administrative

#### Panel 1: Methods

We restricted our analysis to the 15 pre-2004 countries of the European Union (EU)<sup>17</sup> in view of the scarcity of data for other countries and space constraints, and, more importantly, to draw meaningful comparisons between nations with similarly structured health-care systems and outcome measures. We restricted the scope to child health services that helped to differentiate health-care system performance in European countries, especially in the community setting, and excluded rare disorders that need highly specialised care. Although we acknowledge that there are wider determinants, such as social and cultural factors implicated in causation and devising of solutions, in-depth discussion is beyond the scope of this paper.

This paper builds on work about child health services in Europe. We did comprehensive reviews of the medical literature; search strategies differed for each topic but included searching PubMed and relevant reports published by WHO, the UN, EU, and Organisation for Economic Co-operation and Development, and European professional societies.

We define children as people aged 18 years or younger. However, because of poor data availability, some comparisons are restricted to children younger than 14 years. We focused discussion on children older than 1 year because health needs and services for infants often implicate factors outside the scope of this paper—eg, maternity services. However, some analyses inevitably are for the age range 0–14 years; more comprehensive data, when possible, is provided in the appendix.

To compare the 15 pre-2004 countries of the EU, we focused on WHO child mortality data because of reliability and availability. Morbidity data, although desirable, can be unreliable for international comparisons, and are infrequently available. Many comparisons were limited by poor availability of data. When specific examples about services are provided, they were selected from countries that have good outcomes, and from countries that have made progress in development of services or analysed what has been done.

support; common training and education opportunities; and shared values with, and effective leadership by, respected individuals (appendix).

By contrast, systems to deliver care to children with chronic disorders have attracted little attention. Panel 2 provides information about a range of models in the EU15. A key finding is that close cooperation between services, as has been developed in Sweden and the Netherlands, does not arise spontaneously but requires supportive policies backed up by adequate funding.

### First-contact care

One of the greatest challenges facing health professionals working with children is how to distinguish potentially serious illness from minor problems. 17–57% of patients attending emergency departments have problems that are judged to be non-urgent or minor by clinicians and could have been dealt with in primary care.<sup>28–32</sup> However, the high death rate from some acute disorders (eg, meningococcal and respiratory diseases) in some countries suggests that there are also children who need acute specialist care but do not get such care sufficiently quickly.<sup>1,33</sup> The challenges associated with first-contact care are further exemplified by childhood cancer. Prompt diagnosis is crucial but can be difficult because cancer is rare. Cancer will be diagnosed on roughly 3–5 children in a health district (with a population

**Panel 2: Models of care for children with chronic disorders****Sweden**

Chains of care supplement multiprofessional primary care centres, where general practitioners, paediatricians, and children's nurses work closely together. The system was developed as a response to fragmentation of care resulting from excessive decentralisation of services with professionals working in separate organisations. Early assessments showed problems with weak incentives for collaboration, perceived challenges to power structures, and conflicting values in participants (especially physicians). Implementation was eased by giving patients roles as active participants, allowing sufficient time for change, developing supportive policy and financing instruments, and maintaining motivation by focusing strongly on quality improvement.<sup>19</sup>

**France**

Patients with disorders from a specified list—so-called *affections de longue durée*—receive coordinated care according to national standards. Children with chronic disorders receive personal treatment plans with lists of investigations and interventions covered by health insurance. Enrolled children receive routine care for the specified disorder from a specialist service, although parents can choose any doctor for acute exacerbations. Coordinated planned care is through multidisciplinary appointments in health centres or specialist institutes.

**Netherlands**

Transmural care, a collaborative, integrated system of care delivered by professionals working together within and outside hospitals, in mutual agreement and according to patients' needs, is provided. Health professionals have explicit individual and shared responsibilities—eg, specialist nurses manage hospital admission and discharge planning. Assessments of transmural care have been mixed; evidence of discontinuity between primary and secondary care persists, and organisational integration did not always lead to clinical and service integration.<sup>20</sup> The Dutch model is evolving, with greater attention to the importance of financial incentives to collaborative working.

**UK**

The UK system is based around clinical networks, Team Around the Child, and the Quality and Outcomes Framework. Various formal and informal networks have been set up, but few assessments have been done. Consensus views of the difficulties encountered include resistance to change, little evidence of benefits, financial disincentives to cooperation (promoting competition instead of collaboration), and organisational boundaries preventing cooperation between providers.<sup>21</sup> Team

Around the Child is a programme run by the UK Department for Education that focuses on children with complex social and educational needs, and has little input from the health sector. It has been criticised for being overly bureaucratic.<sup>22</sup> The Quality and Outcomes Framework is a pay-for-performance system in general practice that incentivises chronic care treatment of adults, but contains almost no measures for children.<sup>23,24</sup>

**Italy**

In Italy, the quality of services for children with long-term health-care needs differs widely across regions. The best models foster integration across a continuum of care, from primary care, which is provided by family paediatricians, to general hospitals and referral centres; they also provide social and educational support through specific agreements between health authorities, municipalities, and school authorities. Assistenza Domiciliare Pediatrica is a bridge between specialist centres, community services provided by health districts, and family paediatricians, ensuring that as much care as possible is delivered at home. The system is increasingly widely implemented and focuses on chronic disorders necessitating parenteral nutrition, oxygen therapy, physiotherapy, or frequent blood sampling, for example.<sup>25</sup>

**Germany**

In Germany, general paediatricians with an interest in a particular chronic disease—eg, asthma, allergies—provide care in practices or hospitals. Specialised paediatricians, who coordinate care for children with complex or rare chronic illnesses, work in teams with other professionals, such as nurses, dietitians, and physiotherapists. Pneumologists, for example, care for children with all forms of severe respiratory illness, including infections, asthma, and cystic fibrosis. Pathways are organised on the basis of individual patients, and children rarely have several appointments in different places and on different days. Children with developmental disorders, epilepsy, behavioural disorders, learning difficulties, and all forms of chronic diseases who have additional psychosocial problems receive care through social paediatric centres staffed by multidisciplinary teams of paediatricians (mostly specialised in neuropaediatrics), psychologists, physiotherapists, occupational therapists, speech therapists, and social workers. Social paediatric centres are usually colocated with hospitals to ease transfer of acutely ill children. Coordinated multidisciplinary care in Germany is helped by funding packages of care with a single provider organisation rather than the standard fee-for-service model.<sup>26</sup> ModuS is a teaching programme for patients and families that aims to integrate management of chronic disorders into everyday lives.<sup>27</sup>

of around 330 000) per year, so the likelihood of a general practitioner (GP) encountering a child with cancer is low, and depends on the type of service.<sup>34</sup> Primary care paediatricians who look after children only will be more likely to have experience of rare diseases than will a typical

GP, for whom children represent roughly 25% of patients. On average, GPs will encounter a child presenting with cancer once every 20 years.<sup>34</sup> Achievement of a safe and effective balance between skills and access, while avoiding over-investigation, is challenging.

We will focus on four important issues for children's first-contact care: organisation of services; professionals and training; skill mixing; and out-of-hours care. European countries differ strikingly in their organisation of children's (non-hospital) first-contact services. Three main models exist, and are based on whether primary care general physicians, primary care paediatricians, or combinations of both are primarily responsible for care. However, comparisons between models are difficult because of the subtleties and complexities of definitions of these models. For example, in many countries, first-contact care services do not provide a gate-keeping function and access to paediatricians is unrestricted. Furthermore, although Sweden's model could be defined as GP-delivered, it differs substantially from that in the UK. Most GPs in Sweden receive at least three months' specialist training in paediatrics (GPs are required to train either in paediatrics or in gynaecology and obstetrics) and often work closely with paediatricians and children's nurses, with whom they might be colocated in health centres. By contrast, the UK has a more segregated model with GPs who might not have received any specific training in paediatrics beyond that received as an undergraduate, and who work separately from paediatricians. The potential consequences of inadequate paediatric training and supervision of child health clinicians in Europe are shown by an inquiry into child deaths which drew attention to failures in recognition and management of severe diseases.<sup>33,35</sup>

The most recent and comprehensive data for first-contact services and professionals for children comes from the European Paediatric Association's survey of 46 European countries (appendix). This study revealed a substantial diversity of service models, showing countries' different approaches to achievement of a balance between expertise and accessibility. 11 countries of the EU15 provide 5 or more years of training for paediatricians. A 3 year so-called common trunk of general training, including training for primary and secondary care, is followed by a further 2 years of training for specialty work or primary care, or both. This system is intended to ensure that primary care paediatricians are prepared for the diversity of clinical and social problems that they will encounter and that specialist paediatricians receive sufficient training in rare and complex disorders. GPs usually train for at least three years with a minimum 6 month requirement in both a hospital specialty and primary care for the general population.<sup>36,37</sup> Although 13 European countries have extended family-doctor training to 4 years or longer, training in child health remains highly variable between countries.<sup>38,39</sup> Many constraints to training are not related to education—eg, European Union (EU) working-time limits and the availability of training posts. Analyses of data for training have been insufficient to establish whether these variations correlate with competencies and ultimately with child health outcomes attributable to services provided by these professionals.

Increasingly, much routine and some specialist care for children is delivered by nurses. Nurses lead many services in Sweden's child health-care centres; GPs, paediatricians, psychologists, therapists, and dentists are called upon when needed. In the UK and the Netherlands, nurses provide community-based care for children with asthma, which seems at least as effective as that delivered by a GP or paediatrician,<sup>40–42</sup> and might be less expensive. The rising prevalence of eczema has stimulated interest in nurse-led care because outcomes seem similar whether delivered by nurses or specialist doctors.<sup>43,44</sup>

Several European countries have instituted substantial changes to how primary care services are provided outside working hours. Reforms in Denmark, the Netherlands, and the UK led to centralised systems in which large groups of GPs provide care.<sup>45</sup> In Spain, paediatricians in primary care work closely with GPs in a system of multidisciplinary clinics. Other countries are beginning to develop similar services. For example, the Italian system is evolving towards a more cooperative model. Nurse-led telephone triage for children in the Netherlands seems to be as effective as the same service for adults (as measured by return consultations), although outcome data are unreported.<sup>45</sup>

Evidence from Denmark suggests that a new model based on large cooperatives of GPs, with direct out-of-hours access via telephone to GPs, led to a fall in home visits, increased telephone consultations, and an initial but unsustainable 16% decrease in costs. Patients' satisfaction decreased after the changes, but within 3 years was almost back to initial rates. However, how different models of out-of-hours care affect clinical outcomes in children is unclear.<sup>46</sup> The challenges associated with provision of out-of-hours first-contact care for children in the UK were brought into sharp focus after the national employment contract for GPs changed in 2004. Rises in emergency department attendances and short admissions in children around this time might have been related to changes in provision of out-of-hours care, and emphasise the crucial role of first-contact care and consequent effects on the rest of the health service.<sup>47</sup> Yet the 30% rise in child admissions between 1999 and 2010 for acute infections usually managed in primary care suggests that several factors probably contributed.<sup>48</sup> Other health-care changes during this period include the implementation of a 4 h wait target in emergency departments and the commissioning of walk-in centres.<sup>48</sup> Concerns about quality of care for children and training standards also emerged, because doctors working in other EU countries were recruited to provide out-of-hours primary care in the UK—a situation which drew attention to general concerns about EU regulations that allow free movement of professionals between countries despite differences in training.<sup>49</sup>

### Whole-systems plan

Although some successes in the improvement of the health of children in Europe have been noted, much



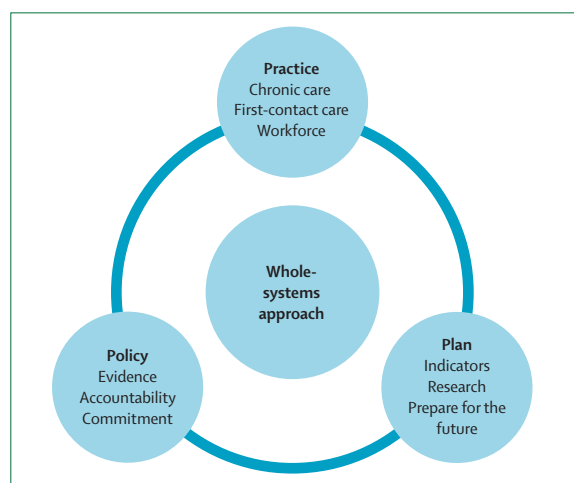


Figure 6: A 3x3 whole-systems plan for European child health

more remains to be done to improve services and ultimately health. Changes in practice are contingent on supportive planning and policy. A whole-systems approach is needed. Problems that need action can be thought of as a 3x3 plan with three general themes—practice, plans, and policy—each with three specific actions (figure 6).

### Practice

#### Chronic care model

The preceding sections have shown the substantial scope to change the ways in which care is delivered to children and their families. In view of the growing numbers of children with chronic disorders in Europe, development of models of care for children is a major priority. This development will be a substantial change from a hospital-centric model to a model in which primary care and secondary care providers and public health services work closely together. Focusing on efforts on prevention of non-communicable diseases and improvement of outcomes of care will necessitate a sustained commitment from bodies representing paediatricians, GPs, child and adolescent psychiatrists, and other health-care professionals (eg, policy makers) at national and European levels. These changes can build upon lessons learned, for example, in the Netherlands, Sweden, and the UK.

#### First-contact care

The noted variation in outcomes of childhood disorders and appropriateness of emergency contacts and admissions suggests a clear need to learn from experience. Sweden's flexible model of first-contact care might offer important lessons in view of Sweden's achievement of some of the best outcomes for children in Europe. Italy, where primary care paediatricians provide most primary care for children, also has high-quality outcomes and offers an opportunity for comparison to and contrast with

Sweden. Although paediatric specialists working in primary care are more expensive to train than are GPs and barriers still exist between primary and secondary care, these problems might be balanced by better outcomes. In the UK, some GPs do not have much postgraduate training in paediatrics and deliver first-contact care separately from paediatricians. Although the strengths of this model have been celebrated,<sup>50</sup> some evidence of suboptimum outcomes for children has been reported. Exploration of flexible approaches that preserve the best qualities of the family medicine approach are thus worthwhile.

### Workforce

The EU provides for free movement of health professionals on the basis of the principle of mutual recognition of qualifications. However, training standards are mainly based on the duration rather than the content of learning. Standards for competencies of child health professionals, particularly those working in first-contact care, need to be defined. In many countries, progress in development of shared curricula and approaches to learning have been limited by deep divisions between professional groups, which in some cases are backed up by legal constraints or inappropriate financial incentives. These issues will come to the fore because the trend for task-shifting from doctors to nurses will probably continue. Children's health professionals should find ways to overcome structural and cultural barriers to work towards a transformative model of health-professional education needed for sustained progress in child health improvement.<sup>51</sup>

### Plans

#### Indicators

Meaningful understanding and international comparisons of the health needs of children and the ways in which health systems respond necessitate appropriate data. Development of indicators for children is particularly challenging because of the so-called four Ds—ie, developmental change, dependency, differential epidemiology, and demographic patterns—which are unique issues in children's health and lives.<sup>52,53</sup> To ensure that indicators are transferable between countries is important. Examples of progress include the Organisation for Economic Co-operation and Development's Health Care Quality Indicator Project, which has some indicators relevant to children (eg, immunisation cover); WHO's Health for All Database; and the European Collaboration for Healthcare Optimisation project, which will allow comparisons between health systems based on hospital databases but has little information about children.<sup>54,55</sup> Additionally, several time-limited research projects have provided information that can inform indicator development—eg, Child Health Indicators of Life and Development (CHILD), which consist of key indicators<sup>56</sup> covering the life course and aspects of primary, secondary, and tertiary prevention and policy. Finally, the EU has agreed a selection of structural

indicators for measures including access to care for vulnerable children such as asylum seekers, and indicators for the protection and promotion of child rights.<sup>57</sup> However, few Europe-wide indicators are specifically designed for assessment of children's primary and secondary care services.

Some countries have made attempts to develop measures for examination of the quality of primary care—eg, management of ambulatory-sensitive disorders and avoidable hospital admissions. In Spain, a list of primary-care-preventable hospital admissions is available that includes several illnesses relevant to children (eg, immunisation-preventable diseases, pneumonia).<sup>58</sup> In Italy, frequency and choice of antibiotic use has been used as an indicator of quality of paediatric care and professional continuing education.<sup>59</sup> The UK has quality indicators (linked to a general practice pay-for-performance system) for some primary care services, but less than 3% of these indicators are relevant to children. New indicators for health outcomes in children and young people, including some specifically for aspects of primary and secondary care, will now supplement existing ones.<sup>28</sup> The Dutch College of General Practitioners developed 139 indicators from 61 clinical guidelines, including several for children relating to asthma, non-traumatic knee disorders, otitis media with effusion, and fever.<sup>60</sup> The UK Outcomes Framework<sup>61</sup> includes a reduction in unplanned hospital admissions for children's chronic diseases and lower-respiratory-tract infections as health improvement targets, showing growing recognition internationally among policy makers of the importance of reductions in avoidable admissions.

Future challenges include devising of indicators of positive aspects of child health instead of those exclusively focusing on health deficits. Development of indicators for complex disorders is important because such illnesses often necessitate interventions from several agencies acting in partnership, and thus measures that are sufficiently sophisticated to encompass all these contributions are needed. Development of indicators that measure the quality of services provided to especially vulnerable children and young people—eg, those who are victims of maltreatment, have mental illness or disabilities, or live in the care of state social systems—will also be important. Some of these indicators are being developed in EU-wide projects.<sup>57</sup>

Children are often an afterthought when health information systems are created (eg, the UK Quality and Outcomes Framework) and in clinical guidelines and service planning. Data deficits are one explanation; political will is another. A compendium of child health indicators enables some comparison, but indicator sets need to be supplemented and based on reliable and uniform systems for data collection and analysis to allow meaningful comparison of the quality of health services for children across Europe. Such a compendium would greatly help with efforts to improve services.

## Research

Research about health services for children is in its early stages.<sup>62</sup> For example, only 5% of all research about cancer relates to children.<sup>63</sup> 11–80% of all paediatric prescribing is estimated to be off label, partly because of the paucity of clinical trials in children.<sup>64</sup> What research is done focuses disproportionately on the most complex disorders. Between 2000 and 2009, the number of Cochrane systematic reviews relevant to children increased by 18%, but the number of reviews applicable to childhood illnesses in primary care increased by only 2%. Although non-drug interventions have an important role in primary care, they were the focus of less than half the reviews assessed.<sup>65</sup> Only a tenth of the reviews assessed focused on interventions to prevent and cure mental health problems, despite the growing burden of mental illness in children and adolescents.<sup>66</sup> Systematic attempts to measure the quality of child health services have been made in the USA,<sup>67</sup> but few similar examples are available in European countries.

Some hopeful signs have been noted, however. A project funded by the EU that includes 29 countries is compiling an inventory of child health research in Europe and identifying emerging priorities for future funding. Europe has the infrastructure in place (eg, networks of longitudinal pregnancy and birth cohort studies) to research important issues in child health. Some countries, such as Denmark, Finland, and Sweden, have benefited from linking of several data sources from primary and secondary care and social services, but this setup is unusual. Practice-based research networks have yielded promising results in the UK, Italy, and some other countries.<sup>68</sup> The Standards for Research in Child Health initiative is intended to improve the quality, ethics, and reliability of paediatric clinical research and has published its first six standards.<sup>69</sup> Similarly, the EU-funded Global Research in Paediatrics (GRiP) Network of Excellence was launched in 2011 to enable the safe use of children's medicines and create international standards for paediatric research.

Although these initiatives signal a growing awareness of the importance of child health research, individual countries and EU-wide bodies are needed to strengthen investments in child health and health services research, focusing particularly on underexplored subjects, such as improvement of the understanding of how childhood illness is dealt with by different health systems, for example quality measurement in primary care, meaningful comparisons of first-contact models, development of chronic care systems, and strengthening of child health policy research.

## Future scenarios

Similar to how climate change experts study future scenarios for global warming, child health experts should develop modelling techniques to examine the future of child health, thus enabling far-sighted policy making. Undoubtedly such exercises would be complex, but analysis of three broad aspects would be a start—

For more on the **inventory of child health research** see <http://www.childhealthresearch.eu>

For more on the **Global Research in Paediatrics (GRiP) Network of Excellence** see <http://www.grip-network.org>

For more on the **compendium of child health indicators** see <http://www.childhealthresearch.eu>

### Panel 3: A rights-based approach to child health services

The 1989 UN Convention on the Rights of the Child is directly relevant for child health and development.<sup>75</sup> It allows disease and ill health to be understood in the context of environmental and societal threats to children. Crucially, the Convention enables children to be considered in their own right. Clinicians and policy makers should strive to realise children's rights to:

- a high standard of health care
- have special needs attended to if disabled
- have their best interests considered and not face discrimination in the health-care system
- have their privacy and confidentiality respected
- receive direct and appropriate information about their disorders
- be able to participate in discussions and decisions.

Practical measures include incorporation of children's rights into strategies and health development plans, establishment of advocacy committees for children, appointment of children's ombudsmen, and assurance that government ministers with special responsibility for children are appointed. The Council of Europe has adopted a resolution to promote child-friendly health care; countries need to follow through on these commitments.

specifically, trends in health status, social determinants of health, and technological developments. Increases in risk factors—eg, low birthweight, obesity, unhealthy lifestyles—and increases in chronic disorders, such as mental health disorders, cancer, and non-communicable diseases, are likely to impede improvement in child health. Prevention of non-communicable diseases is a major goal of all health systems, and should become a prominent feature of country strategies and policies, especially in times of financial strain. Technological advances, such as genomic medicine, are unlikely to be sufficient on their own to address many of the lifestyle-related chronic illnesses in children—eg, obesity, hypertension, and dyslipidaemia—but advances such as new instruments for point-of-care diagnosis and monitoring of chronic disorders might be useful. Plans need to be sufficiently flexible to incorporate such developments.

### Policy Evidence

The UN Convention on the Rights of the Child offers a framework for policies to support child health and wellbeing,<sup>70</sup> and the European Council has issued guidelines on child-friendly health care.<sup>71</sup> However, much more could be done to translate these high level goals and supporting evidence into policies at the national and European levels. Investment in child-centred public health interventions and social policies will improve health and reduce inequities and accumulate advantages for individuals and populations throughout the life course.<sup>72</sup> Social protection for the earliest years of life and the most vulnerable and disadvantaged children is particularly important during the most severe financial crisis for decades, to reduce the likelihood that children's health and wellbeing will be adversely affected.<sup>73</sup>

Provision of universal access to high-quality, affordable early years education is a key strategy for reduction of social inequalities. Such universal access is only an aspiration for disadvantaged children in many countries, especially those in marginalised groups such as the Roma and undocumented migrants.

### Accountability

Accountability is crucial if the voices of children are to be heard effectively, and it can be strengthened through a framework of monitoring, reviewing, and remedying of processes.<sup>74</sup> National oversight mechanisms, with responsibility for child health services, should be put into place and tasked with devising of action plans to address problems that arise. We propose that countries should identify a few context-relevant indicators for child health services and appoint a monitoring organisation with open and transparent responsibility for collection and analysis of data. A national child health oversight committee should report to a minister of state responsible for child health, who should regularly review progress based on data and be able to implement remedying action.

### Commitment

Policy makers often seem reluctant to translate into policies the increasing evidence showing that the foundations of life-long health are built through greater investments in the early years of life and by adopting an approach to policy making consistent with the goals of the UN Convention on the Rights of the Child (panel 3). Until national and European governing bodies are willing to accept this challenge, the outlook for child health in Europe will remain uncertain.

### Implementation of 3x3 plan for European child health

The arrangements for delivery of health care in the EU are the responsibility of member states, even though many of the inputs into delivery systems, such as health professionals, drugs, and technology, are subject to European law. Furthermore, some risk factors in children and young people are also subject to EU laws and policies—eg, tobacco, food, and alcohol consumption. The EU has substantial influence through its convening power and the Framework Programmes that fund health research. It can also do much to make the health needs of children visible, by working through the Eurostat database,<sup>76</sup> and the European Health Interview and Examination Surveys under development and by building on the findings of the first Child Health in the European Union report,<sup>77</sup> to create a permanent on-line database of child health. Finally, the EU, together with the European Central Bank and the International Monetary Fund, is implementing wide-ranging economic policies that are having severe consequences for the health of everyone, including children, in the countries worst affected by the financial crisis, yet is failing to assess the health effects of its policies.

Real and sustained improvements in child health in Europe can happen if political will across the EU can be brought to bear on the problems facing children now and in the future.

#### Contributors

IW conceived the paper at the request of MM, and wrote the first draft. MT, PG, GT, MB, AvdB, JE, MP-M, SJ, and MM revised the paper. MK did the data analysis, with contributions from MM, IW, and PG.

#### Conflicts of interest

We declare that we have no conflicts of interest. IW is married to Richard Horton, Editor of *The Lancet*. Richard Horton had no role in the peer-review and acceptance processes for this paper.

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# A Strategic Pediatric Alliance for the Future Health of Children in Europe

Stefano del Torso, MD<sup>1,2,3</sup>, Massimo Pettoello-Mantovani, MD<sup>1,4,5</sup>, Alfred Tenore, MD<sup>1,6,7</sup>, Zachi Grossman, MD<sup>1,6,8</sup>, Ingrid Wolfe, MRCPCH, FFPH<sup>1,9</sup>, and Jochen Ehrich, MD DCMT(London)<sup>1,4,10</sup>

Rising indebtedness has refocused the debate around European healthcare reform to focus on cost-saving. Will reforms enable Europe's healthcare systems to tackle the challenges of demographic and epidemiologic changes, rising demand for healthcare, and an increasing focus on quality improvement? Or will the pressures to deliver more for less inevitably drive cost-cutting, more rationing, and risk declines in quality and access of care? How can we reshape the debate on European health care reform to encourage a new vision of health? These and other key questions were raised and debated at a recent forum convened by *The Economist* Conferences in Geneva in March 2011. The alarming conclusions later published by *The Economist* in a report entitled, "The Future of Health Care in Europe," paint a very bleak picture (Figure).<sup>1</sup> The pressure on European healthcare systems is likely to have a differentially greater effect on vulnerable groups such as children. Yet children feature very little in a forum like *The Economist* Conferences and in general health systems debates throughout Europe.

European health care systems need to adapt to ongoing financial pressures, while at the same time evolving better to suit changing health care needs of children as chronic conditions become increasingly dominant problems.<sup>2</sup> For example, in response to current global economic pressures, many countries are considering changing from a pediatrician-delivered primary care system to a general practitioner model as a cost-cutting exercise, rather than in response to evidence about quality.<sup>3,4</sup> Different possible "extreme scenarios" have been described<sup>1</sup> in response to the likelihood that substantial changes in health care will unfold for European healthcare in the next 20 years. Three of these scenarios include: (1) European nations joining forces to create a single pan-European healthcare system; (2) preventive medicine taking precedence over acute care for sick patients; and (3) European healthcare systems focusing on vulnerable members of society. The first scenario we judge to be unlikely, given the diversity of primary care systems for children in Europe. The second scenario focuses on prevention, already an integral part of a pediatrician's principal function. The third possibility should include the elderly patients and the very young as the most vulnerable members of society. Unfortunately, children and their unique needs are all too often forgotten in wider health systems discussion and policy planning.

Children are not just small adults. Their health, development, and health care needs are distinct and merit consideration as such. Investment in the early years, with adequate recognition of the unique qualities and requirements of children and young people, will reap the largest rewards across the life course.<sup>5</sup>

Although there are pressures on European countries to cut health care costs, and one way of doing so may be to evolve towards a general practitioner model, which is perceived as less expensive, the evidence points towards the benefits of integrated teams of trained child health professionals working collaboratively in primary care.<sup>6</sup>

## The Strategic Pediatric Alliance

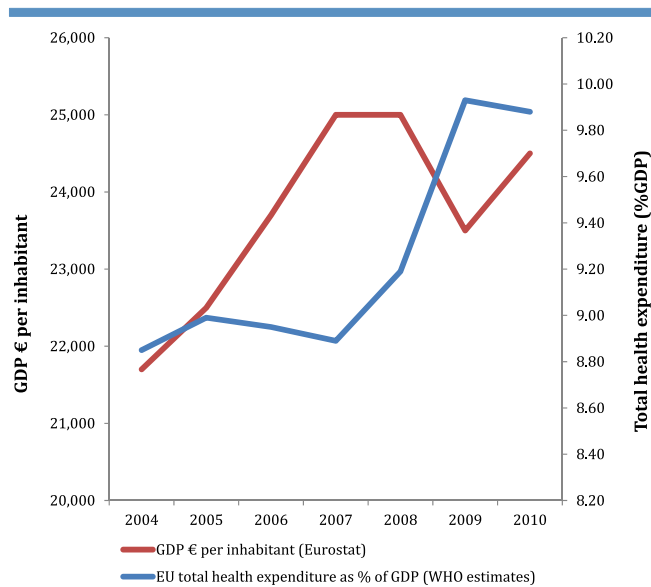
A Strategic Pediatric Alliance (SPA) for the future health of children in Europe was formed by the three major European Pediatric Organizations: European Paediatric Association, European Academy of Paediatrics, and European Confederation of Primary Care Paediatricians joining forces to urgently and effectively address the current lack of public attention to the future health of children in Europe. The SPA has the support of many national European pediatric societies and associations, with the intent of promoting the importance of a collective effort to strengthen the research evidence and advocacy efforts in order to more effectively influence the opinions of governmental administrators, politicians, and European Union Institutions.

The foundations of the SPA were laid down during the 1st International Conference on Pediatric Primary Care, held in May 2011 in Tel Aviv, Israel, and officially developed as a consortium in the course of the 5th Europaediatrics Congress held in Vienna on June 2011. SPA is a consortium, not an additional pediatric organization in the European scenario. It is an alliance action network among existing major European associations, societies, and confederations established to

From the <sup>1</sup>Strategic Pediatric Alliance, Padova, Italy; <sup>2</sup>European Confederation of Primary Care Pediatricians—Confédération Européenne de Pédiatrie Ambulatoire, Lyon, France; <sup>3</sup>Strategic Pediatric Alliance, Secretariat, Great West House, Great West Road, Brentford, United Kingdom; <sup>4</sup>European Paediatric Association—Union of National European Paediatric Societies and Associations, Berlin, Germany; <sup>5</sup>Department of Pediatrics, University of Foggia, Foggia, Italy; <sup>6</sup>European Academy of Paediatrics—European Union of Medical Specialists, Brussels, Belgium; <sup>7</sup>Clinica Pediatrica, Università degli Studi, Udine, Italy; <sup>8</sup>Maccabi Health Services, Tel Aviv, Israel; <sup>9</sup>European Centre on Health of Societies in Transition, London School of Hygiene and Tropical Medicine, London, United Kingdom; and <sup>10</sup>Children's Hospital, Hannover Medical School, Hannover, Germany

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**Figure.** European Union (EU) Health Expenditure and growth domestic product (GDP). Source: World Health Organization (WHO) Health for All database, Eurostat.

better coordinate efforts in the defense of children and their health. The consortium is open to the major international and national European child health societies/associations/confederations with the objective of promoting strong advocacy and political intervention in order to ensure the delivery of high quality health care to children throughout Europe.

The SPA's activities will focus on research projects, publications, policy papers, and advocacy efforts, all aimed at ensuring that the voices of children and young people are heard in the increasingly urgent debate around European health care reforms.

### First Steps

The SPA has embarked on a Europe-wide research project to map the current organization of pediatric primary care. Preliminary results were presented and discussed at an SPA meeting held in Prague in May 2012. A position paper will

be generated as a result of this work, on which to base discussion on the most effective next steps for SPA in order to create strong and effective political interventions and advocacy for the children of Europe with special reference to the primary care settings, because a strong primary care system represents the best opportunity to protect the health of Europe's children.

### Conclusion

At no other time in the history of Europe has it been more important for pediatricians to be effective advocates for children. Pediatricians offer valuable insights into the complexities of the different phases of a growing child and the unique health needs of children. The main European pediatric organizations (European Paediatric Association, European Academy of Paediatrics, and European Confederation of Primary Care Paediatricians) strongly believe that unifying their efforts in the SPA will provide a strong voice to speak on behalf of Europe's children in developing an adequate response to the current challenges that European child health care is facing. ■

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## Diversity and Differences of Postgraduate Training in General and Subspecialty Pediatrics in the European Union



Massimo Pettoello-Mantovani, MD, PhD<sup>1,2</sup>, Jochen Ehrich, MD, DCMT(London)<sup>2,3</sup>, Arturo Romondia, MD<sup>1</sup>, Luigi Nigri, MD<sup>1</sup>, Luciano Pettoello-Mantovani, IB<sup>4</sup>, and Ida Giardino, MD<sup>1</sup>

The European Union (EU) has progressively expanded the number of its member nations throughout the years. Since its founding in 1993, the number of its members has grown from the initial 6 nations to 28 nations (EU28) in 2013, therefore including more than one-half of the nations belonging to geopolitical Europe. This political achievement has been paralleled in many European nations by the emergence of cultural values awareness and strong feelings for the preservation of the various local cultural profiles, including traditions, history, and cultural roots. The preservation of the identitarian profiles and cultural diversity of the local systems, which characterize Europe, is generally assumed as a capital for its development<sup>1</sup> and often may influence the decisions in many fields, including medical education.

The equation of how to amalgamate a multiplicity of consolidated cultural backgrounds, all becoming acceptable to each local reality and its historical profile, will keep the EU institutions busy for many years. Of course, several additional factors must be taken in account when discussing cultural diversities vs homologation, which we would leave to a more extended study. It is also not an easy task to find examples in different geopolitical areas that could inspire solutions on how to deal with diversities and differences that often are difficult to be reconciled.

This is the articulated basic scenario that provides the stage for the analysis of the current status and future perspectives of many institutional structures in Europe, including medical education, specifically postgraduate education.

The management of medical education in the EU28 would require appropriate coordination, backed by an adequate cultural knowledge, a balanced strategic vision, and constant supervision. EU does not have a clearly identified administrative structure devoted specifically to medical education, and the responsibilities in this area are shared by different departments or agencies of the European Commission, including the Directorates General of Education and Culture, Health and Consumers, Internal Market and Services, and the EU Education, Audiovisual, and Culture Executive Agency.

The traditional Kissingerian question, “Who do I call to speak to Europe?,” still seems to be relevant and applicable to the specific case of European medical education.

Currently, in relations with the EU28, the various European national associations of medical subspecialties, including pediatrics, have a major advocate in the European Union of Medical Specialists (Union Européenne des Médecins Spécialistes [UEMS]), a private nongovernmental organization regulated by Belgian law. UEMS has been active since 1958 with the aim to represent national associations of medical specialists and operate at the European level to defend and promote the interests of medical specialists, the free movements of medical specialists, and the quality of medical care.<sup>2,3</sup> Following the well-recognized general notion that the issue of quality, quality assurance (QA), and quality improvement (QI) in medical education are of paramount importance, not only for the benefits of medical students and doctors but primarily for the health of citizens, UEMS has devoted its efforts to developing European standards in postgraduate medical specialist training. Among the aims of this nongovernmental organization is to harmonize the various national curricula, promote unifying criteria to which the training centers should conform, and ultimately foster a European board of examination.<sup>3</sup>

A satisfactory and reliable QA and QI of postgraduate medical education has a foundation in comparable educational goals among different systems. In absence of these factors, any sincere effort to pursue a credible QA and QI standardized analysis in higher education applicable throughout the European Nations may be in vain. The considerable diversities and differences among the independent medical educational systems in the EU28 thus seem to represent a major obstacle to a proper and dependable QA and QI assessment.

The case of pediatric postgraduate education provides scholastic evidence that the achievement of comparable and assessable medical education systems is not an easy task to

EU	European Union
EU28	European Union 28 nations
QA	Quality assurance
QI	Quality improvement
UEMS	Union Européenne des Médecins Spécialistes (European Union of Medical Specialists)

From the <sup>1</sup>Postgraduate Pediatric Residency Program, Residents Committee, University of Foggia, Foggia, Italy; <sup>2</sup>European Paediatric Association, Union of National European Paediatric Societies and Associations, Berlin, Germany; <sup>3</sup>Children's Hospital, Hannover Medical School, Hannover, Germany; and <sup>4</sup>Undergraduate School, Bachelor Course in Economics, Management and Finance, Bocconi University, Milan, Italy

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be accomplished in the EU28. The original data included in the [Table](#) (available at [www.jpeds.com](http://www.jpeds.com)) show how the postgraduate pediatric training is currently (2014) performed in the EU28 nations. The 28 different national programs last from 4 to 8 years and present strikingly diversities. We have arbitrarily divided the nations into two groups: Group A includes nations that offer a 4-year basic course in general pediatrics and in some cases an additional 1-3 years optional training in selected pediatric subspecialties, and Group B includes nations that offer a 5- to 8-year basic course in pediatrics, including general pediatrics and part of pediatric subspecialties, which in some cases may be further expanded by 1-3 years of specific subspecialty training. The educational system in the Group B nations is intended to ensure that primary care pediatricians are prepared for the diversity of clinical and social problems that they will encounter and that specialist pediatricians receive sufficient training in rare and complex disorders.<sup>4</sup>

The profound diversities among the EU28 postgraduate pediatric programs are attributable to a multiplicity of factors, some of which were discussed previously. Such factors also may include the significant differences that exist among the various pediatric health care systems, particularly in the organization of children's (nonhospital) first-contact services, and it may also reflect the attention put by some nations in providing a specific postgraduate education particularly focused on general and primary care pediatrics. In fact, the management of first-contact services is a well-recognized social issue in the EU28, subjected to the frequent changes in political visions and policies of single nations, and frequently impacted by economic contingencies. The 3 existing main models are based on whether primary care general physicians, primary care pediatricians, or combinations of both are primarily responsible for care. However, comparisons between models are difficult because of the subtleties and complexities of definitions of these models.<sup>4</sup> The pressure to "deliver more for less" often seems to be the driving force forging the political strategic decisions in the area of pediatric health care and pediatric education, rather than social, cultural, and economic sensitivity and competences.

Therefore, the delivery of appropriate pediatric training seems not to be related exclusively to educational motivations but also to other factors, including social, economic, and political rationales. EU working-time limits and the availability of training posts also play a significant role, although the economic factors seem to be predominant. In response to current global economic pressures, and often in obedience to generalized budget restrictions imposed by local financial policies, ongoing discussions are taking place in many countries that are considering changing the structure of their postgraduate pediatric training. An equivocated interpretation of an EU directive on training in pediatrics<sup>5</sup> has offered many EU28 nations the justification to consider reducing the pediatric training to just 4 years, presenting it as the best length for a postgraduate training in pediatrics. In reality, the EU directive pointed to the complete different

goal of protecting the quality of pediatric education by establishing a minimum period of training. The aim was to avoid unacceptable reductions of the pediatric training's length below the limit of 4 years, which would affect the basic quality standards for education in this area.

Higher education in general has been placed at the center of public debates as a result of the recent economic crisis. The role of improving education on all levels and in all professions has been identified as a theoretical factor that—when adequately implemented in the curricula—may be able to react positively against the threats of ongoing economic and social crises. However, most of the discussion failed to mention the negative impact of the economic crisis on higher education in the "real world." In fact, the economic crisis has legitimized the long-existing argument that higher education should be treated the same way as any other service in the economy and, as such, education should be subject to ever-more accountability and managerial practices. The ongoing discussions aiming at minimizing the length of postgraduate pediatric education in some countries, seem to follow a current trend of unhealthy rationalization, with an emphasis on "cutting the excess fat" and "balancing the budget," instead of following constructive concerns aimed at providing the proper health care to children, supported by properly trained professionals.<sup>6</sup>

In summary, there is a complex challenge that the future of pediatric health care in Europe may be characterized not only by a shortage of pediatricians but also by a shortage of very well-trained newly accredited pediatricians. Furthermore, the EU28 may have an increasing free circulation of medical professionals with an even more limited training in child health care such as general practitioners caring for children. Last, but not least, there will be the need to guarantee excellence in pediatric education and to provide better quality and safety of health care for children. The evidence of a profound diversity of postgraduate pediatric training programs among the EU28 should be carefully considered and addressed, as a propaedeutic approach to ensure the appropriateness and feasibility of any QA and QI assessment program and ultimately to ensure a satisfactory and appropriate level of pediatric health care for European children in future decades. ■

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(Lithuania), Johannes B. Van Goudoever (The Netherlands), Jiri Zeman (Czech Republic).

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Reprint requests: Massimo Pettoello-Mantovani, MD, PhD, University of Foggia, Via L. Pinto, 1, Foggia, Italy. E-mail: [mprm@unifg.it](mailto:mprm@unifg.it)

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**Table. Pediatric postgraduate medical education and training in the EU28 (2014)\***

Group A	Group B
<b>4 years basic course in general pediatrics<sup>†</sup> (additional 1-3 years training in pediatric subspecialties are optional)</b>	<b>5-8 years basic course in pediatrics (including general pediatrics<sup>†</sup> and part of pediatric subspecialties)</b>
<p>In the countries listed herein, the 4 years of training in general pediatrics enables MDs to practice general pediatrics and may include, in some cases, a short training in a few subspecialties.</p> <p>After gaining a degree as a general pediatrician, additional training in various pediatric subspecialties is optional. To obtain a pediatric subspecialty diploma, the training must be performed in a pediatric subspecialty center, not in adult centers.</p> <p>The duration of the subspecialty training varies from 1 to 3 years among the different countries and it depends on the type of subspecialty selected.</p> <p>The number and kind of pediatric subspecialties approved to issue habilitation certificates, differ from country to country.</p> <ul style="list-style-type: none"> <li>• Bulgaria</li> <li>• Cyprus</li> <li>• France</li> <li>• Greece</li> <li>• Spain</li> </ul>	<p>The countries listed below generally follow the basic postgraduate medical education structure of 3 + 2 years' course.</p> <p>Typically, the structure of the courses includes 3 years of training in general pediatrics (common trunk), and 2 years of elective training and rotations in pediatric subspecialties, as well as research training and diagnostic skills, having a variable design and implementation between and within the different countries. The basic period of training of 5 years may be extended with further optional subspecialist training ranging from 1 to 3 years.</p> <ul style="list-style-type: none"> <li>• Austria (6 years)</li> <li>• Belgium</li> <li>• Czech republic</li> <li>• Croatia</li> <li>• Denmark</li> <li>• Estonia</li> <li>• Finland (6 years)</li> <li>• Germany</li> <li>• Hungary</li> <li>• Ireland (7 years)</li> <li>• Italy</li> <li>• Latvia</li> <li>• Lithuania (6 years)</li> <li>• Malta</li> <li>• The Netherlands</li> <li>• Poland</li> <li>• Portugal</li> <li>• Romania</li> <li>• Sweden</li> <li>• Slovakia</li> <li>• Slovenia</li> <li>• United Kingdom (6 years)</li> </ul>

**Notes**

- Austria: 6 years, which include a number of mandatory subspecialties plus 1 year in a nonpediatric specialty. Training may be extended by 2 or more optional years, depending on the type of subspecialty selected.
- Bulgaria: In parallel to the 4-years training course in general pediatrics, different 4-year training courses are established for each of the following recognized pediatric subspecialties: cardiology, pneumology, neonatology, endocrinology, rheumatology, neurology, nephrology, and gastroenterology. Such courses include 2 years of general pediatrics integrated by 2 years in one subspecialty selected by the trainee.
- Czech Republic: The training in general pediatrics lasts 5 years. Subspecialist training is optional and requires an additional 2 years of training. However, the last of the basic 5-year curriculum in general pediatrics may be included in the subspecialty training if it is spent in a clinical department accredited for the subspecialty selected.
- Denmark: The 5-year training in pediatrics includes 1 year of introductory training in general pediatrics, followed by 4 years of further pediatric training (2 + 2 years) in 2 different accredited pediatric departments. Although Denmark does not recognize pediatric subspecialties, trainees may expand their education in pediatric subspecialties from 6 months up to 3 years depending on the type of subspecialty selected.
- Estonia: 3.5 years of training in general pediatrics is followed by 1.5 years or rotation in selected subspecialties. Ongoing changes will soon include a mandatory 1 year of training ("general residence") for all postgraduate courses, including pediatrics, that will include family medicine and emergency medicine. This will increase the postgraduate training in pediatrics to 6 years.
- Finland: The 6-years' training course in general pediatrics includes the first 3 years spent in central hospitals followed by 3 years in a university hospital. General pediatricians may become subspecialists by taking an additional 2-year course in one of the following: neonatology, allergology, cardiology, endocrinology, hemato-oncology, gastroenterology, infectious diseases, rheumatology, nephrology, or social pediatrics.
- Germany: 5 years of basic training in pediatrics, including part of pediatric subspecialties, plus 1-3 years of subspecialty training, depending on the type of subspecialty selected (one of the 3 years is a subspecialty course [eg, pediatric nephrology] may be included in the initial 5-year training period).
- Hungary: The 5-year training course includes 2 years of training in general pediatrics, followed by 3 years of rotations in pediatric subspecialties. An additional 2 years of training are required to obtain a diploma in one of the pediatric subspecialties accredited.
- Ireland: 2 years of training in general pediatrics, including 6 months in neonatology, followed by 5 years of higher specialist training.
- Italy: Ongoing discussion are taking place at government level aimed at reducing the pediatric training to 4 years, including general pediatrics and perhaps rotations in a few selected subspecialties. Pediatric subspecialties are not officially recognized.
- Latvia: 4 years of training in general pediatrics, plus 2-3 years of subspecialty training, depending on the type of subspecialty selected.
- Lithuania: After 6 years of training, including 4 years of general pediatrics and 2 years in a selected pediatric subspecialty, two separate diplomas are issued: one in general pediatrics, and another in the pediatric subspecialty selected for the training.
- Malta: The last year of the 5-year training in pediatrics is performed in the United Kingdom.
- Poland: Pediatric training is currently 6 years, followed by additional separate training for pediatric subspecialties of typically 3 year. The system is in transition to adapt to the 5-year structure, including the common trunk (3 years), followed by 2 years of training to become specialist in general pediatrics, or 2-3 years of training in a selected subspecialty to become a specialist in general and subspecialty pediatrics. However, it still will be possible to perform 2-3 years of training in a pediatric subspecialty after 5 years of training in general pediatrics to acquire the additional diploma in a pediatric subspecialty.
- Romania: The training in general pediatrics lasts 5 years with no common trunk. Subspecialties are optional and performed after the 5th year in separate programs.

*(continued)*

**Table. Continued****Notes**

- Slovakia: 3 additional years of training are currently required to obtain a diploma in a pediatric subspecialty. Ongoing discussions are taking place at the governmental level aimed at reducing the basic pediatric training to 4 years.
- Spain: Pediatric training follows the postgraduate education structure of 3 years dedicated to general pediatrics, followed by a 1 year rotation in selected subspecialties.
- Sweden: 5 years of general pediatrics plus 2 optional years of elective subspecialties.
- United Kingdom: the postgraduate medical education in pediatrics includes 2 initial years of general medicine. The total length of training is 6 years, and it could be extended up to 8-9 years, depending on the type of subspecialty selected.

\*Data in this table were collected with the collaboration of the European Pediatric Association, Union of National European Pediatric Societies and Associations, the European Medical Association (<http://www.emanet.org>), and representatives of the EU28 Ministries of Health, national pediatrics societies, associations, and postgraduate courses in pediatrics.

†The training in general pediatrics is ill defined in most countries and may include training periods within hospitals, dispensaries (polyclinics), private practices, seminars or self-study that may differ in duration and content from country to country and within countries. The training periods include primary, secondary, and tertiary pediatric care; however, the training may be organized following a rather strict schedule or an optional mode. Luxembourg does not offer postgraduate training in Pediatrics, however the specialty in Pediatrics is included in the list of medical disciplines recognized in Luxembourg. Training in Pediatrics is performed abroad based on agreements with European Universities from different EU countries (Austria, Belgium, France, Germany, Switzerland, and the United Kingdom). Luxembourg only recognizes Pediatric trainings of 5 years' minimum. Trainees may spend 1 or 2 years training in a pediatric department in Luxembourg and at least 3 years abroad in university hospitals. Luxembourg also offers a complete training for general practitioners performed locally, with at least 2 months of training in Pediatrics conducted in an accredited pediatric department.

# Learning across Borders: Advocacy of Pediatricians in Public Health Response during a Recent Wild Poliovirus Transmission in Israel

Zachi Grossman, MD<sup>1,2</sup>, Itamar Grotto, MD, PhD, MPH<sup>3,4</sup>, Diana Tasher, MD<sup>5</sup>, Michal Stein, MD<sup>5</sup>, Ehud Kaliner, MD<sup>3</sup>, and Eli Somekh, MD<sup>2,5</sup>

Israel has been certified as polio-free by the World Health Organization, and since 2005, its routine immunization schedule consists of inactivated poliovirus vaccine (IPV) only. At the end of May 2013, the Israeli Ministry of Health has confirmed the reintroduction of wild-type poliovirus 1 into the country. Documented ongoing human-to-human transmission necessitated a thorough risk assessment followed by a supplemental immunization activity (SIA) campaign using bivalent oral polio vaccine (bOPV). The unusual situation in which ongoing poliovirus transmission was picked up through an early warning system of sewage monitoring without active polio cases, brought about significant challenges in risk communication.<sup>1,2</sup>

## Challenges

The communication of the need for a SIA to the public faced several challenges.<sup>2</sup> The remote chance of vaccine-associated paralytic poliomyelitis (VAPP) because of the reintroduction of oral polio vaccine (OPV) into an IPV-only country caused antivaccination movements to strongly oppose the SIA. There was a critical need to face them and respond to their arguments both in the traditional media (newspapers, television) and in the new media (internet, social networks). These movements also appealed to the Supreme Court against the vaccination campaign but eventually were turned down.

The re-introduction of OPV was challenging for several reasons, especially because there were no clinical cases of poliomyelitis, and, therefore, arguments such as why to bother when “viruses are only in sewage” were common. These challenges posed a major risk of a Halo effect on the routine vaccination program: objection and mistrust related to bOPV campaign could have spread to other vaccines.

## Adverse Effects

The possibilities of VAPP and future circulation of vaccine-derived polioviruses strains were heavily considered. It was also expected that a mass vaccination campaign would be

accompanied by serious temporal side effects and allegations that these events were related to the administration of bOPV. In addition, introducing bOPV during an era of growing populations of immune-compromised children and adults brought up questions regarding the attendance of these children at daycare and school when their school-mates have been vaccinated with bOPV.

## Stigmatization of the OPV

Since the vaccine was taken out of routine vaccination in 2005, descriptions such as “the dangerous vaccine” were quite common in the press and electronic media. bOPV was attacked by vaccine opponents as a “new” and “investigational” product, which was not tested properly by clinical trials. Parents were exposed to information and misinformation regarding the dangers of OPV from multiple media sources.

## Protecting the Community

Candidates for OPV were basically protected. The target population for bOPV vaccination was children who were already immunized with IPV to prevent the circulation of wild poliovirus (WPV). bOPV was not administered to children who had not been vaccinated previously with IPV to prevent cases of VAPP. This strategy created an unprecedented situation. The vaccine was prescribed to children who were already protected from paralytic polio to protect other portions of the society.

## Role of the Israel Pediatric Association

The Israel Pediatric association collaborated with the Ministry of Health during and following the vaccination campaign.

## Reaching a Consensus among Pediatricians

The main motive was that when the parents are flooded with information regarding OPV vaccination they may seek the advice of their pediatricians to decide whether to vaccinate

bOPV	Bivalent oral polio vaccine
GBS	Guillain Barre syndrome
IPV	Inactivated poliovirus vaccine
OPV	Oral polio vaccine
SIA	Supplemental immunization activity
VAPP	Vaccine-associated paralytic poliomyelitis
WPV	Wild poliovirus

From the <sup>1</sup>Maccabi Health Services, Tel Aviv, Israel; <sup>2</sup>Israel Pediatric Association, Pediatric Infectious Disease Unit, Edith Wolfson Medical Center, Holon, Israel; <sup>3</sup>Public Health Services, Ministry of Health, Jerusalem, Israel; <sup>4</sup>Faculty of Health Sciences, Ben Gurion University of the Negev, Beer Sheva, Israel; and <sup>5</sup>Pediatric Infectious Disease Unit, Edith Wolfson Medical Center, Holon, and The Sackler School of Medicine, Tel Aviv University, Tel Aviv, Israel

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their children. The leadership of the association was consulted through all stages of the campaign. Detailed scientific and guidance material was periodically e-mailed to all Israeli pediatricians and posted in the association's website.<sup>3</sup> In addition, the leaders of the association took part in regional conferences with local pediatricians and family physicians. An interactive discussion between pediatricians and key opinion leaders took place in the Israel Pediatric Research in Office Setting Network mailing list. Throughout the campaign, questions sent by pediatricians relating to specific vaccination scenarios were answered at the same day by the leadership of the association.<sup>4</sup>

### Community Outreach

Leaders of the organization visited the main areas of WPV circulation to personally and openly discuss with the local communities the importance of OPV vaccination. The Israeli Pediatric Association prepared printed material that was delivered in public areas and the local press that included explanations regarding the reason for vaccination with OPV. This material was published both in Hebrew and Arabic.

### Television and Social Networks

The leaders of the Association took an active role in the media campaign for the SIA. They were frequently interviewed and also participated in television debates with vaccination opponents.<sup>5</sup> Members of the association were active in social networks to identify and face misinformation regarding the vaccination campaign.

### A Response to Crisis

During the SIA, 4 vaccinated children were diagnosed with neurologic manifestations that were claimed by vaccine opponents to be attributed by to the OPV. There were 3 cases of Guillain Barre syndrome (GBS) and 1 case of acute disseminated encephalomyelitis. These cases were broadly covered by the press and electronic media. Some of the parents were interviewed and accused that OPV administration was the reason of their children's problem. A special expert panel was nominated by leadership of the association to examine the possible association of these neurologic manifestations with the vaccination. The final report of this committee concluded that there was no association between the vaccine and the neurologic manifestations<sup>6</sup> based on the following: (1) rate of GBS among vaccinees was not higher than the rate in the general population; (2) total number of cases of GBS in 2013 (the year of the vaccination) was actually lower than in previous years; and (3) other causes for GBS—like *Campylobacter Jejuni* infection—were finally isolated in most of the cases. The report of this panel was sent to all pediatricians and received a broad coverage by the national press and assisted in discontinuation of these accusations.

### Lessons

This unprecedented public health event highlights the possibility of a reintroduction and transmission of wild polio in a

highly vaccinated IPV country. There was no earlier reference to learn from and it was like “inventing the wheel.” The environmental surveillance proved crucial both for early detection and for monitoring the intervention. The successful concerted national public health response was achieved by reaching a consensus among health care professionals, consultation with external experts, and proactive risk communication to the public in all forms of media (including internet and social networks) and to community leaders finally reached a high national vaccination rate with bOPV of 79% among the target population.

### Implications for Europe

In addition to the detection of poliovirus in Israel, an outbreak of paralytic poliomyelitis was reported in Syria in October 2013, where vaccination coverage has dramatically decreased during the civil war. In addition, a paralytic case of polio was identified in Iraq.<sup>7</sup> These events increase the threat of reintroduction of WPV into the European Union and European Economic Area.<sup>8</sup> European Center for Disease Prevention and Control recently has issued recommendations for European Union member states to take several steps to face polio threat including considerations regarding the possible usage of OPV upon introduction of WPV to European country.<sup>9</sup>

We believe that when an OPV campaign is considered in an IPV-based country in response to WPV detection, the Israeli experience with the recent mass OPV campaign may assist the decision makers and the professional societies in successful handling of such a public health crisis, especially when approaching the polio “end-game.” ■

Reprint requests: Zachi Grossman, MD, Maccabi Health Services, 3 Hausner St, Tel Aviv, Israel 69372. E-mail: [zgrosman@netvision.net.il](mailto:zgrosman@netvision.net.il)

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## 7th Europaediatrics - Florence, Italy, May 13-16, 2015

Terence Stephenson, MD<sup>1</sup>, and Massimo Pettoello-Mantovani, MD, PhD<sup>2</sup>

The 7th Europaediatrics Congress ([www.europaediatrics2015.org](http://www.europaediatrics2015.org)), which will take place in Florence, Italy, from May 13-16, 2015, is the highlight of the activities of the European Paediatric Association, the Union of National European Paediatric Societies and Associations (EPA-UNEPSA). Taking place every 2 years, this flagship event of EPA-UNEPSA is the meeting point of general pediatricians and pediatric subspecialists, not only from Europe but from all over the world. The scientific program of Europaediatrics 2015 is being developed in close collaboration with several major European subspecialty societies (Table).

### Invitation to Europaediatrics 2015

Planning for this important international scientific meeting is now well underway and we hope that you will join us at the 7th Europaediatrics Congress in May 2015 for what will be an innovative and interactive educational program. The meeting, which is being held in Florence, one of the most beautiful and cultural cities in Italy, will bring together almost 2000 pediatricians and other child health professionals from Europe and the rest of the world to share learning, expertise, and ideas.

The program for the congress is being developed by the Europaediatrics 2015 Scientific Committee. This 7th biennial meeting will have an innovative format, with a mixture of plenary presentations by international child health experts and guideline sessions led by the European specialist societies, which will give general pediatricians an opportunity to bring themselves up to date with the best evidence-based practice. The theme of sharing good practice will be continued in the more interactive personal practice sessions where leaders in their fields will present their approaches to the management of important pediatric conditions.

There also will be an opportunity to listen to debates, view posters, and participate in workshops and discussions on topics of relevance to the wider aspects of the health and well-being of children and young people worldwide, such as diversity, equity, and children's rights.

The conference will be accredited with the relevant European educational programs so delegates will be able to register for continuing medical education/continuing professional development points/credits. We particularly hope

that Europaediatrics 2015 will be an occasion for those in the early stages of their careers to meet new colleagues and forge lasting friendships across Europe, as well as for others colleagues to renew old friendships. When the scientific program is over for the day, the setting for the Congress in the Fortezza da Basso in the center of Florence offers opportunities for delegates to visit world-renowned museums and art galleries or just to stroll the streets and take in the views and the history in the city, which was the cradle of the Renaissance.

Further details of the program and the registration to the meeting are described on the Europaediatrics Congress website [www.europaediatrics2015.org](http://www.europaediatrics2015.org) and on the EPA-UNEPSA website [www.epa-unepsa.org](http://www.epa-unepsa.org).

### The Journal of Pediatrics Contributes to Europaediatrics 2015

EPA-UNEPSA is pleased to announce that the leadership of *The Journal of Pediatrics* has planned to significantly contribute to Europaediatrics 2015, with a number of activities to be included in the scientific program. In a plenary lecture, Thomas R. Welch, MD, Associate Editor of *The Journal* and Chair of the Department of Pediatrics at the Upstate Medical University, Syracuse, New York, will speak about the "Five papers that have most changed pediatrics in past 15 years." Furthermore, Welch will discuss "stupid paediatric tricks" during an interactive "personal practice" session. This is a review of 4 well-established therapies in pediatrics, which have recently been shown to be harmful.

The contribution of the leadership of *The Journal* to the scientific program of Europaediatrics 2015 is highly regarded by the European paediatric community and it will further strengthen the solid collaboration between *The Journal* and EPA-UNEPSA. ■

EPA-UNEPSA The European Paediatric Association, the Union of National European Paediatric Societies and Associations

From the <sup>1</sup>Chairman of the 7th Europaediatrics Scientific Committee, Institute of Child Health, UCL, London, United Kingdom; and <sup>2</sup>European Paediatric Association, Union of National European Paediatric Societies and Associations (EPA-UNEPSA), Berlin, Germany

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**Table. 7th EUROPAEDIATRICS, 2015: “Learning Across Borders”**

MAIN TOPICS:	
PLENARY LECTURES/SYMPOSIA <ul style="list-style-type: none"> <li>• Vaccine strategy for Europe</li> <li>• Adolescentology</li> <li>• Insulin resistance</li> <li>• Diabetes</li> <li>• Antibiotic resistance</li> <li>• Early nutrition</li> </ul> PROS/CONS DEBATES <ul style="list-style-type: none"> <li>• Treatments by new drugs in children</li> <li>• High sugar drinks and taxes</li> <li>• Obesity</li> </ul>	EDUCATIONAL SESSIONS <ul style="list-style-type: none"> <li>• E-learning</li> <li>• How to write an abstract</li> <li>• Networking of pediatricians to do research in ambulatory setting</li> <li>• How to analyze and present scientific data</li> </ul> PUBLIC HEALTH SESSIONS <ul style="list-style-type: none"> <li>• Health care services in Europe</li> <li>• Child’s right to health</li> <li>• New millennium development Goals/update and new visions</li> </ul>
GUIDELINES AND PERSONAL PRACTICE SESSIONS (IN COLLABORATION WITH MAJOR EUROPEAN SUBSPECIALTY SOCIETIES) <ul style="list-style-type: none"> <li>• Vaccinations and vaccination in children with chronic diseases                (ESCMID - <i>European Society of Clinical Microbiology and Infectious Diseases</i>)               <ul style="list-style-type: none"> <li>• Transfusion (red cells/platelets)/sickle cell disease                    (EHA - <i>European Haematology Association</i>)</li> <li>• Nutrition/gastroenteritis/coeliac disease—“Learning the e-learning” course                    (ESPGHAN - <i>European Society of Pediatric Gastroenterology Hepatology and Nutrition</i>)                   <ul style="list-style-type: none"> <li>• Asthma                        (ERS - <i>European Respiratory Society</i>)</li> <li>• Neurology issues in neonatology—neonatal seizures/underwater delivery                        (UENPS - <i>Union of European Neonatal and Perinatal Societies</i>)</li> <li>• Injuries in childhood—management of mild head injury (PECARN rules)/advanced life support update/management of young febrile infants                        (EUSEM - <i>European Society of Emergency Medicine</i>)</li> <li>• Standard care for children with cancer                        (SIOP - <i>International Society of Paediatric Oncology</i>)                       <ul style="list-style-type: none"> <li>• Vasculitis                            (ESPN - <i>European Society for Paediatric Nephrology</i>)</li> <li>• Arthritis—treatment of juvenile idiopathic arthritis                            (PRES - <i>Paediatric Rheumatology European Society</i>)</li> <li>• Rickets/congenital hypothyroidism/delayed growth and puberty/GH treatment                            (ESPE - <i>European Society of Paediatric Endocrinology</i>)</li> <li>• Management of headaches/developmental delay                            (EPNS - <i>European Paediatric Neurology Society</i>)</li> </ul> </li> </ul> </li> </ul> </li> </ul>	



# The Dilemma of International Pediatric Congresses in Europe: Starting the Debate

Jochen Ehrich, MD, DCMT (London)<sup>1,2</sup>, Detlef Stengritt, MD<sup>2</sup>, Daniel Jaeger, MD<sup>2</sup>, Leyla Namazova-Baranova, MD<sup>1,3</sup>, Massimo Pettoello-Mantovani, MD, PhD<sup>1,4</sup>, and Simon Lenton, FRCPC<sup>1,5</sup>

National and international medical congresses are an integral part of continuous professional development for health scientists and clinicians. Two publications, however, have raised considerable concern about their value<sup>1</sup> or whether they are merely “a profit making enterprise.”<sup>2</sup> Medical congresses are becoming larger, more luxurious, and expensive, and, as a result, their cost-benefit ratio may be decreasing.

This review discusses the future of international pediatric congresses and how they can contribute to the education of pediatricians. The European Paediatric Association leadership outlines how the challenges may be tackled by using innovative strategies for future pediatric congresses.

## Two Scenarios

Three major European pediatric organizations, which represent both local and national pediatric societies and associations and more than 200 000 pediatricians working in 53 European countries with a total population of more than 200 million children and young people, include the European Academy of Paediatrics, European Confederation of Primary Care Pediatrics, and European Pediatric Association–Union of National European Paediatric Societies and Associations (EPA-UNEPSA). In addition, there are more than 20 European pediatric subspecialty societies that organize congresses for both pediatric specialists and generalists.

We have used EPA-UNEPSA data from 1976 to 2013 to illustrate the issues for general congresses, as well as European Society for Paediatric Nephrology (ESPN) data from 1967 to 2008 for subspecialist meetings. Congresses held by EPA-UNEPSA have attempted to keep pace with the evolving epidemiology of childhood conditions and education needs of pediatricians, using evidence on effective learning methods.<sup>3</sup> The strength of EPA-UNEPSA congresses was to link international experts and encourage collaboration between the members of national pediatric societies. In addition, EPA-UNEPSA encouraged individual pediatricians to transfer learning from the international congresses to their national opinion and pol-

icy makers. The emphasis of the congress is to translate evidence into practice at both policy and service levels. EPA-UNEPSA congresses are attended by 1500-2000 pediatricians, which is less than 1% of all European pediatricians.

This relatively low proportion of pediatricians attending may be related to the high costs of international meetings, which primarily affect pediatricians in training and for those pediatricians living in countries with limited resources. The costs for travel, accommodation, registration, and participation in the social program often exceed a total of €1000. The application for a Schengen visa created considerable hurdles for pediatricians from Eastern countries traveling to the West. It is unclear to what extent sponsored travel by the pharmaceutical industry may have aided some pediatricians with limited financial resources, but such practice raises serious ethical concerns. The official EPA-UNEPSA congress language has always been English and professional translation into other languages is rarely offered, thus making the participation difficult for those general pediatricians lacking solid English skills. In addition, there has been an increasing competition among international pediatric congresses for attracting participants.

A total of 34 ESPN congresses were held between 1967 and 2000, 9 of 34 as joint congresses in cooperation with the International Pediatric Nephrology Association (4 were held in Europe). The median congress duration was 3 days. The total number of accepted abstracts during 25 congresses held in Europe was 3257. The total number of presentations increased annually (Figure 1; available at [www.jpeds.com](http://www.jpeds.com)). The mean number of total presentations per day increased from 11 in 1967 to 119 in the year 2000. The mean number of free oral communications increased from 9 to 20 per day, the relative proportion of oral presentations decreased from 94% to 16%, and the percentage of posters increased from 0 to 73% (Figure 1). The proportion of speakers from East Europe delivering oral communications was lower than from European Union countries. Unpublished data of ESPN show that three-quarters of 113 congress presentations of a European meeting in pediatric

CME	Continuous medical education
EPA-UNEPSA	European Pediatric Association–Union of National European Paediatric Societies and Associations
ESPN	European Society for Paediatric Nephrology
ISR	International social responsibility
PCO	Professional congress organizers

From the <sup>1</sup>European Paediatric Association, Union of National European Paediatric Societies and Associations (EPA-UNEPSA), Berlin, Germany; <sup>2</sup>Children's Hospital, Hannover Medical School, Hannover, Germany; <sup>3</sup>Scientific Centre of Children's Health, Moscow, Russia; <sup>4</sup>Institute of Pediatrics, University of Foggia, Foggia, Italy; and <sup>5</sup>Child Health Department, Bath, United Kingdom

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nephrology in 2002 were published 1-5 years after the congress (Figure 2; available at [www.jpeds.com](http://www.jpeds.com)).<sup>4,5</sup> However, only one-third of 344 accepted abstracts were published as a full paper in a journal, which may be to the result of several factors, including a questionable reliability of early results presented at the congresses.

### Causes of Low Attendance to International Pediatric Congresses in Europe

In 2009, obligatory continuous medical education (CME) had become standard in slightly more than one-third of European countries; however, if failure to achieve CME requirements was not followed by sanctions in the majority of European countries, the value is questionable. Another reason for the absence of pediatricians at international congresses was the fact that the culture of learning across borders appears to be lacking in European countries.<sup>6</sup> Last but not least, registration at a congress did not necessarily mean that all pediatricians actively participated at the sessions.

### Face-to-Face vs Webinar Type of Meetings

Despite significant improvements in communication (eg, videoconferencing, webinars) there remains an imbalance of information between pediatricians working in resource-poor nations, generally in Eastern Europe, with those working in more affluent systems. As in the past, international congresses will remain an integral part of the function and role of professional organizations. Ioannidis states, “conferences organized by medical societies are characteristic features of the academic, professional, and social life of all health related disciplines,”<sup>1</sup> including pediatrics. The literature would suggest that the traditional format of plenary session speakers followed by free papers has been of great importance for the active scientific cooperation of experts dealing with health care.<sup>7</sup>

This type of highly specialized meeting between leaders in the fields of research relevance of pediatrics and child health no doubt has a role in providing CME aimed at improving access to effective, evidence-based interventions. Similarly, high-quality health care today requires a multidisciplinary, sometimes a multiagency team to support the child and family members. There is a cogent argument that teams who work together should train together.

The role for international meetings is not disputed.<sup>8</sup> “There is no substitute for meeting in the flesh,”<sup>9</sup> which is a view reinforced by Drife,<sup>10</sup> who accepted that conferences can provide inspiration, motivation, and stimulation far better than videoconferencing. The questions that arise relate to clarifying the role of international meetings vs national meetings: how these meetings can best be used to focus on the issues most important to European children and families and how the content, structure, and methods used in these meetings can be improved to increase the effectiveness and value for both children and professionals.

International meetings offer the potential to understand and address differences in policy and practice between different nations. Why would one immunization schedule

be different from another when using the same vaccines? Why would injury prevention have a higher priority in one nation compared with another? Why do the rights of children and families have a greater emphasis in one country?

There is ample evidence to suggest that effective learning depends on active participation rather than passive engagement. There is increasing evidence based on the efficacy and efficiency and overall impact of different teaching and learning methods in health care. Cochrane data showed that the educational meetings alone or combined with other interventions can improve professional practice and health-care outcomes for patients.<sup>7</sup> Using this evidence would help structure international meetings to increase their effectiveness and value. Combining plenary review sessions with topic-based symposia and personal practice sessions that engage the audience with discussions about health service design and allocation of resources are more effective than a guest speaker alone.

This evolution from passive learning to active learning requires a substantial change in thinking and practice from organizers, speakers, and participants. Invited speakers and participants should be committed to active learning through measurement, reflection, innovation, and improvement appropriate to local settings.

The experience from EPA-UNEPSA and ESPN congresses may be different from that of other subspecialist pediatric congresses held in Europe, but it is likely that they demonstrate trends that are similar for most specialist meetings.

We cannot judge whether smaller congresses are better than larger meetings, or vice versa. The problem with international meetings is the large numbers of participants, papers, and concurrent sessions; their size limits the number of venues available to host such a meeting. These venues tend to be in more affluent countries with greater ancillary costs, such as catering and accommodation. For the general pediatrician, selecting appropriate presentations to attend from a large menu can be difficult, especially when venues within the congress are separated by a significant distance. Often the opportunities to discuss a particular topic and learn from innovative approaches and collective creativity are extremely limited.

### International Social Responsibility

Corporate social responsibility is defined as actions that organizations can undertake on a voluntary basis, over and above a minimum legal requirements, to address the company’s sense of responsibility toward the community and environment in which it operates. The organizers of medical conferences also should think more widely about the people and the planet as well as profit.<sup>8,11</sup> The greatest need for postgraduate training and continued professional development lies in the east of Europe, in the less well-resourced nations. There is not only a discrepancy between “where conferences are held” and “where they are needed,” but also in the purpose and content of such meetings. These less-resourced nations often have a legacy of limited East-West collaboration. Yet it is in these nations—where more than one-half of all European children live

and pediatricians work—that have most benefit from international knowledge about evidence-based clinical interventions, learning through innovation and improvement, and ongoing collaboration between centers.

The concept of corporate social responsibility is well-established in the commercial world and a parallel theme of international social responsibility (ISR) could be included in the mandate for medical organizations in better resourced nations to share their knowledge and expertise with less-resourced professionals and professional organizations within the boundaries of an expanded Europe. Approaches to improving cross-border health care<sup>12</sup> highlight the importance of cross-border collaboration for the benefit of children with rare conditions requiring subspecialist intervention which is not available in their home countries. The ethical issues related to ISR range from conflicts of interests with regard to financial aspects to conflicts of power, prestige, and purpose.<sup>1</sup> An unknown proportion of medical societies and associations are run by a cadre of leaders dominating the congress programs. Invited speakers may be chosen from a small group of opinion leaders.<sup>13</sup> Disclosure of potential conflicts is worthwhile and a balanced choice of speaker is helpful in fulfilling the criteria of ISR.

If there was a commitment by European organizations to this approach, there should be clear benefits for the nation hosting the meeting. This would include negotiated content, relevant to local circumstances, the use of the most relevant learning methods with ongoing support for local innovation, and improvement to embed new ways of working.

Stringent criteria for selecting who organizes medical congresses is essential.<sup>1</sup> The majority of national and international pediatric societies do not have the permanent internal capacity to organize large international meetings and are therefore reliant upon professional congress organizers (PCO) for this logistical function. PCOs work in the free market and compete against each other for contracts with professional organizations.<sup>13</sup> Some PCOs, however, have now sponsored charitable foundations to organize their own international meetings offering CME, often with high levels of sponsorship or support from private/commercial organizations. Speakers may be proposed from the commercial sector with the intention of influencing the market for health care, drugs, or technology, particularly in the resource poor nation's whose healthcare systems will be expanding in future years.<sup>2</sup> This subliminal influence has largely declined in well resourced nations due to discussion and knowledge about the ethical issues and the development of greater standards limiting unregulated commercial influence.<sup>2,14</sup>

The EPA-UNEPSA view is that PCO conducted meetings may not meet the criteria for ISR and that the primary beneficiaries of international meetings must be the users or providers of services, rather than shareholders of independent PCOs who organize meetings for profit rather than social purpose.<sup>2</sup>

## Conclusions

In summary, pediatric organizations can deliver ISR in relation to congresses if it is embedded in their clear governance

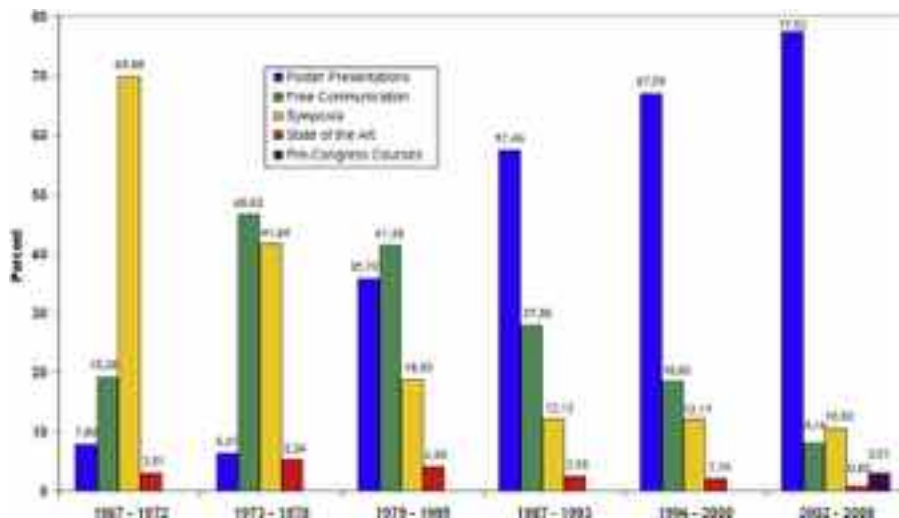
and ethical framework. This strategy is built upon clarity of purpose, clear benefit for the health of the children of Europe, collaboration, professional integrity, and trust. We conclude that there is a requirement to rethink the focus, purpose, methods, location, and costs of future international pediatric congresses such as Europaediatrics. The opportunities to learn through comparative international experience is infinite, ranging from policy to practice, but to achieve real change that benefits the health of children and young people congress organizers should rethink their purpose and focus on "people not profit." Participation in international conferences is expensive<sup>9</sup> and there should be a careful cost-benefit analysis by both organizers and participants regarding the benefits and costs.<sup>1,8</sup>

We feel that the guiding principles for the international pediatric congresses should be "greater value for less investment" using more participative approaches with a focus on "learning across borders and making a difference." A "roundtable forum" during Europaediatrics 2015 in Florence, Italy, for pediatricians representing officially recognized European pediatric societies and associations will discuss these issues. ■

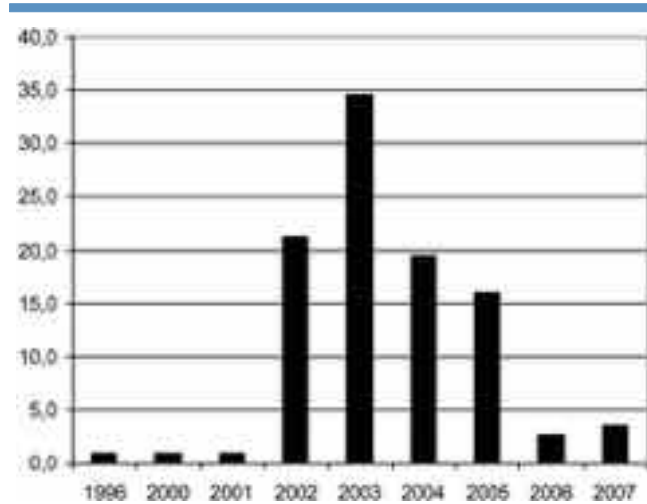
Reprint requests: Jochen Ehrich, MD, DCMT (London), Professor of Pediatrics, University Children's Hospital, Hannover Medical School, European Paediatric Association, Carl Neuberg Str. 1, 30625 Hannover, Germany. E-mail: Ehrich.jochen@mh-hannover.de

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**Figure 1.** Percentage of presentations according to the type of communication at ESPN congresses in 6 time periods from 1967 to 2008.



**Figure 2.** Proportion of subsequent full publications listed in PubMed of 48 free communications and 296 posters presented in 2002 at the European Congress of Pediatric Nephrology. A few accepted communications presented previously published data.

# Establishing a Child Rights, Health Equity, and Social Justice-Based Practice of Pediatrics

Jeffrey Goldhagen, MD, MPH<sup>1</sup>, Raul Mercer, MD, MSc<sup>2</sup>, Gary Robinson, PhD<sup>3</sup>, Ernesto Duran, MD<sup>4</sup>, Elspeth Webb, MD<sup>5</sup>, and Jochen Ehrich, MD, DCMT<sup>6</sup>

The United Nations' Convention on the Rights of the Child (CRC) came into force 25 years ago as the first human rights document focused solely on children.<sup>1</sup> The articles of the CRC are concordant with the underlying precepts of pediatrics and public health. Yet, despite ongoing changes in the social-ecology of health, more than a half-century of enlightenment as to the relevance of human rights to the health and well-being of children, and rapid advances in social epidemiology and the life course sciences, the principles of human rights, health equity, and social justice have not been integrated into health professional training. Neither have they been incorporated into standards for the delivery of health care, development of health systems, and generation of public policy.

To remain relevant, healthcare and health systems must function at the intersection of health and human rights. The availability of rights, equity, justice-based strategies and tools (Table I), and the principles and standards of numerous human rights documents—including the United Nations' CRC (1979),<sup>1</sup> Ottawa Charter for Health Promotion (1986),<sup>2</sup> African Charter on the Rights and Welfare of the Child (1999),<sup>3</sup> and United Nations' Convention on the Rights of People with Disabilities (2006)<sup>1</sup>—make this possible. However, global health systems remain focused primarily on selective strategies to promote child survival in low-income countries,<sup>4</sup> and access to health care and biomedical approaches to health in mid- and upper-income nations. Global public and private sector health policies, systems, and practices have arguably not responded to the complexity of the social, economic, political-civil, environmental, and cultural factors that generate health. They have not engaged rights, equity, and justice-based approaches to health policy, systems, and practice. This chasm between knowledge and experience and policy and practice must be acknowledged and addressed through medical education and research that is informed by the principles of human rights, health equity, and social justice.<sup>5</sup>

Toward these ends, the following general principles are presented to serve as the foundation and framework for the formulation of a rights-, equity-, and justice-based approach to pediatrics. They reflect the norms and stan-

dards of CRC Article 24 and related articles of the CRC addressing children's rights to health (Table II). As presented in the American Academy of Pediatrics Policy on Child Rights and Health Equity,<sup>5</sup> the integration of the principles and tools of human rights, social justice, human capital investment, and health equity ethics into all aspects of the education of child health professionals is necessary to prepare pediatricians to translate these principles and standards into practice, systems development, and the generation of public policies. We refer to this emerging rights-based practice of pediatrics as Community, Social, and Societal Pediatrics (C-SSP)—a practice that is as relevant to subspecialty care as it is to primary care pediatrics.

## Principles for the Realization of Children's Right to Health

Appendix 1 (available at [www.jpeds.com](http://www.jpeds.com)) presents a set of basic premises required for the realization of children's right to health. These principles define the parlance, definitions, documents, epidemiology, science, structure, and strategies that establish the foundation and framework for fulfilling children's rights to health. Appendix 2 (available at [www.jpeds.com](http://www.jpeds.com)) establishes normative standards and models for addressing a rights-based approach to health in the context of requirements for leadership, standards, models, competencies, systems, and youth participation.

Appendix 3 (available at [www.jpeds.com](http://www.jpeds.com)) defines roles and responsibilities for states and professionals, as well as for including children's rights to mental health and early child development, in the realization of children's rights to health.

Appendix 4 (available at [www.jpeds.com](http://www.jpeds.com)) addresses measures, monitoring, and evaluation, which are

From the <sup>1</sup>University of Florida, College of Medicine-Jacksonville, Jacksonville, FL; <sup>2</sup>Program of Social Sciences and Health, FLACSO (Latin American School of Social Sciences), Buenos Aires, Argentina; <sup>3</sup>Child Rights Education for Professionals (CRED-PRO), IICRD, University of Victoria, Victoria, British Columbia, Canada; <sup>4</sup>Observatory of Child Rights, National University, Bogota, Colombia; <sup>5</sup>Department of Child Health, Cardiff University School of Medicine, Cardiff, Wales; and <sup>6</sup>Children's Hospital, Hannover Medical School, Hannover, Germany

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**Table I.** Toolkit for translating the principles of rights, equity, and justice into pediatric practice

Foundational tools	Diagnostic-planning tools	Intervention tools
Human rights documents <ul style="list-style-type: none"> <li>• United Nations' CRC</li> <li>• Covenant on Civil and Political Rights</li> <li>• Covenant on Social, Economic, and Cultural Rights</li> <li>• Convention on the Elimination of all Forms of Racial Discrimination</li> <li>• Convention on the Elimination of Discrimination against Women</li> <li>• Convention against Torture and Other Cruel, Inhuman, and Degrading Treatment</li> <li>• UN Convention on the Rights of Persons with Disabilities</li> </ul> Other source documents <ul style="list-style-type: none"> <li>• Social Justice Principles</li> <li>• Life-Course Science</li> <li>• Alma Ata Declaration</li> <li>• Ottawa Charter</li> <li>• Millennial Development Goals</li> </ul>	<ul style="list-style-type: none"> <li>• Health system framework</li> <li>• Root cause analysis</li> <li>• Budget analysis</li> <li>• Intergenerational justice analysis</li> <li>• Periods of risk analysis</li> <li>• Health impact assessment</li> <li>• Environmental impact assessment</li> <li>• Ethnography</li> <li>• Media/arts/photo voice</li> <li>• Environmental justice</li> <li>• GIS/mapping</li> <li>• Health related quality of life (HRQOL)</li> <li>• Equity indicators</li> <li>• Early childhood development indicators</li> <li>• Children's participation indicators</li> <li>• Logic models</li> <li>• Social capital scales</li> </ul>	Health service/system level <ul style="list-style-type: none"> <li>• Child-friendly hospitals</li> <li>• Gender tool</li> <li>• Cultural competence</li> <li>• Children's participation</li> <li>• Pain and palliative care</li> <li>• Evidence-based practice</li> </ul> Household/community level <ul style="list-style-type: none"> <li>• Ombudsperson</li> <li>• Child-friendly cities</li> <li>• Medical home</li> <li>• Children's participation</li> </ul> Interscotal/policy level <ul style="list-style-type: none"> <li>• Medical-legal collaboration</li> <li>• Human capital investment</li> <li>• Built environment/urban planning</li> <li>• Intergenerational justice</li> <li>• Wealth transfer</li> <li>• Early childhood education</li> <li>• Community-based participatory and translational research</li> <li>• Children's allowances</li> <li>• Evidence-informed policy</li> </ul>

fundamental to the development of new and innovative metrics that relate to the articles of the CRC, child advocacy, social mobilization, participation, etc.

## Conclusion

The relevance of pediatrics and pediatricians to the domestic and global well-being of children will depend increasingly on the extent to which the principles, norms, and practice of child rights, health equity, and social justice are integrated into the mainstream of global child and public health. The principles delineated in [Appendices I-IV](#) provide a foundation and framework for this integration.

The extent to which child health professionals engage a rights, equity, and social justice-based approach to child health will determine the extent to which they lead change for the future of pediatrics. The challenges and opportunities related to children's right to health, including children's right to participation in the health system, communicating with children, and the Council of Europe's child friendly health care model, will be explored in depth in future articles on the European Paediatric Association pages. ■

**References** available at [www.jpeds.com](http://www.jpeds.com)

**Table II.** Core CRC articles and those related to Article 24: Right to Health

Core articles	
Article 2. Non Discrimination	All rights are to be recognized for each child without discrimination on any grounds
Article 3. Best Interests	The best interests of the child should be considered in all decisions related to them
Article 6. Survival and Development	Optimal survival and development
Article 12. Participation	Respect for the child's views in all matters affecting them
Related articles	
Article 5. Evolving Capacities	Rights of parents to provide guidance to the child considering her/his evolving capacity
Article 17. Access to Information	Ensure accessibility of information from a diversity of sources
Article 18. Parental Capacities	State shall ensure parents have the capacity to fulfil the rights of their children
Article 19. Protection from Violence	Protection from maltreatment, and implementation of prevention and treatment programs
Article 23. Disabilities	Right to special care, education, and training to achieve dignity and greatest degree of self-reliance
Article 25. Review of Treatment	Entitlement to have placement of children in care evaluated regularly
Article 27. Standard of Living	Right to a standards of learning (SOL) adequate for physical, mental, spiritual, moral, and social development
Article 28. Education	Right to free primary education, accessible secondary education, and no corporal punishment
Article 29. Education	Right to optimal development of the child's personality, talents, and mental and physical abilities
Article 32. Protection from Exploitation	Protection from work that threatens his/her health, education, or development
Article 39. Recovery of Child Victims	Right to care and social reintegration for child victims of armed conflicts, torture, neglect, etc.

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## Appendix 1. Principles for the realization of children's right to health: basic premises

### BASIC PREMISES FOR THE REALIZATION OF CHILDREN'S RIGHT TO HEALTH

**Principle 1. WHO definition of health.** The practice of *Community, Social, and Societal Pediatrics (C-SSP)* is framed in the context of the World Health Organization's (WHO) definition of health.<sup>2</sup> This will ensure all prerequisites for health and health related quality of life are addressed and fulfilled. This will also expand the focus of pediatrics and pediatricians from "child health" to "children's health and well-being," and impact all aspects of the implementation and measurement of strategies related to the practice of *C-SSP*.

**Principle 2. Human rights documents.** The full complement of human rights documents, including most specifically the UN CRC (1979),<sup>1</sup> Ottawa Charter for Health Promotion (1986),<sup>2</sup> African Charter on the Rights and Welfare of the Child (1999),<sup>3</sup> UN Convention on the Rights of Persons with Disabilities (2006),<sup>4</sup> and related General Comments inform and structure all elements of *C-SSP* practice.

**Principle 3. Health equity and child rights.** The practice of *C-SSP* engages the domains of pediatric practice presented in the AAP policy statement Health Equity and Child Rights<sup>5</sup>: (a) child rights, (b) social justice, (c) human capital investment, and (d) health equity ethics, as core elements of pediatric practice, systems development, and policy.

**Principle 4. Social epidemiology and life course science.** *C-SSP* uses the knowledge and experience of social epidemiology and the life course sciences to inform public and private sector organizations, agencies, institutions, professionals, and other stakeholders how to translate the principles of child rights, health equity, and social justice into the delivery of health services, the development of health systems, and the generation of relevant public policy. In particular, epigenetics provides critical insights into the complex interactions between social environments and gene expression.

**Principle 5. CRC Article 24.** The child's right to health, presented in CRC Article 24 and related articles (Table II), including the core CRC Articles 2 (non-discrimination), 3 (best interests), 6 (survival and development), 12 (participation), and 17 (access to information), serve as the primary principles for the practice of *C-SSP*. Article 24 is arguably among the most complex rights to fulfill, given our understanding of the impact of social and environmental determinants on the health and well-being of children. Advances in knowledge of the impact of child health on adult health trajectories greatly magnify the importance of fulfilling the child's right to health. Thus, in addition to the broad array of related articles within the CRC (Table II), strategies to fulfill children's right to health must also engage other human rights conventions and documents, in particular, those related to the health and well-being of women. Traditionally, women's rights agendas (sexual and reproductive rights) have been separated from children's rights agendas. More recently, we have come to understand the mutuality of respecting both women's and children's rights.<sup>6</sup>

**Principle 6. Health system structure.** Many state and institutional health policies remain grounded in selective primary care (low-income countries), and/or biomedical models focused on access to primary and subspecialty health care (mid- and upper-income countries). Global, national, and regional health policies must establish a rights, equity, and justice-based structure for the delivery of universal health services and related sector systems to address the social and environmental determinants of child health. These services and systems must conceptualize the CRC as a set of standards and norms, strategies, and tools that respond to root-cause determinants of child health and well-being.

**Principle 7. Public health approach.** *C-SSP* adopts a public health approach to fulfilling children's right to health. The US Institute of Medicine's report on the Future of Public Health<sup>7</sup> identifies three core functions of public health—Assurance, Assessment, and Policy—that can be used to frame the efforts of states, professionals, and stakeholders to implement CRC Article 24 and its related articles.

## Appendix 2. Principles for the realization of children's right to health: normative standards and models

### NORMATIVE STANDARDS AND MODELS FOR THE REALIZATION OF CHILDREN'S RIGHT TO HEALTH

**Principle 8. Leadership.** The knowledge and tools exist to transform the structure and function of health services and systems into rights, equity, and justice-based systems of care. *C-SSP* provides the leadership; establishes the goals, objectives and tasks; provides access to tools (Table I); and defines the metrics required to monitor the accomplishment of this transformation. The practice of *C-SSP*:

- Recognizes and addresses the complex interplay of social and environmental determinants of children's health and well-being.
- Establishes the CRC as a tool/matrix that can be used to frame responses to the complex interplay of child health determinants.
- Creates a common health systems framework to analyze and address child health services, systems, and policies.
- Requires states and institutions to identify the root-cause determinants of children's health prior to implementing prevention, promotion, and mitigation strategies.
- Develops and implements rights, equity, and justice-based tools that can be used to advance the health and well-being children.
- Catalyzes the development of curricula to prepare professionals to use/evaluate these tools.
- Ensures child and youth participation.

**Principle 9. Normative standards.** CRC Article 24 and its related articles establish the normative standards for the function of health systems and health outcomes. Public and private sector stakeholders in children's health and well-being must use the CRC articles related to health and, in particular, the core principles of child rights (Articles 2, 3, 6, 12, and 17), to frame, implement, and evaluate all policies, programs, and systems that impact child health. Given the right of all children to health, the impact of health on the realization of all other rights, the societal impact of child health on her/his well-being, and the effects of children's health on the adult life course, the child's right to health must be a priority for states' distribution of resources and other public policies.

**Principle 10. New medical models.** Advances in knowledge and understanding of the impact of social and environmental factors on health, and the biology and physiology underpinning this impact, require parallel changes in strategies to optimize the health and well-being of children and the adults they will become. These strategies must be rights, equity, and justice-based in order to succeed. Fulfilling the elements of Article 24 and its related articles will require new medical models to embrace rights, equity, and justice-based models of health services, systems, and policies.

**Principles 11. Systems-of-care principles.** States should embrace systems-of-care principles with respect to developing, implementing, and evaluating the systems and practices required to fulfill the health rights of children. These principles include the necessity of systems and practices, at a minimum, to be family centered, youth guided, culturally and linguistically competent, and evidence-based.

**Principle 12. Child and youth participation.** Children and youth and, in particular, those marginalized by social and environmental determinants, disabilities, and medical conditions, must be fully engaged in defining, developing, implementing, and evaluating policies, systems, and practices related to the broad spectrum of initiatives required to fulfill their rights to optimal health and well-being. Metrics to measure child and youth participation must be established and used for assessment and quality improvement.<sup>8</sup>



**Appendix 3. Principles for the realization of children's right to health: roles and responsibilities****ROLES AND RESPONSIBILITIES FOR THE REALIZATION OF CHILDREN'S RIGHT TO HEALTH**

**Principle 13. States' responsibilities.** States cannot devolve or relinquish their responsibility to ensure children's right to health through privatization, outsourcing, or other strategies, nor as a result of externally imposed restrictions on their public health responsibilities for assurance, assessment, and policy development.<sup>7</sup> This relates to states' own internally generated policies for privatization of public health programs and health services, as well as internationally imposed policies related to structural adjustment and economic policies.

**Principle 14. Professional education.** The neglect and indifference toward the principles of child rights, equity, and justice in relation to health, and the general disregard of the social and environmental determinants of health and life course sciences in the education of health professionals, have contributed and continue to contribute to the failure to optimize children's health and well-being and reach Millennium Developmental Goals.<sup>2</sup> The continued marginalization of children by race, sexual orientation, age, gender, disability, social status, etc. also contributes to these failures. Child health professionals must be educated in the practice of health and human rights.

**Premise 15. Mental health and early child development.** Mental health has been neglected in the discourse of child health. With advances in knowledge related to brain and early child development, it has become increasingly clear that both child and adult physical and mental health and well-being are determined early in childhood. Implementation of Article 24 must include a focus on children's mental health, including the need to address early brain development, as critical elements of a child's right to health, education, survival, development, and other related rights (Table II). CRC Article 6 and General Comment 7 address the priority of ensuring children's rights to optimal early child development.

**Appendix 4. Principles for the realization of children's right to health: measures, monitoring, and evaluation****MEASURES, MONITORING, AND EVALUATION FOR THE REALIZATION OF CHILDREN'S RIGHT TO HEALTH**

**Principle 16. Metrics.** The metrics used to measure the success of rights, equity, and justice-based approaches to the practice of C-SSP include its capacity to both prepare states, professionals, professional organizations, and other stakeholders to respond to the root causes of contemporary child health determinants; as well as prevent and mitigate future health issues (eg, the impact of globalization and climate change on children).

**Principle 17. Levels of indicators.** The practice of C-SSP establishes two levels of rights, equity, and justice-based indicators: (a) outcome indicators that can be used as metrics across and within countries, and (b) proximal determinant indicators that can be used to address root cause determinants unique to individual communities.

**Principle 18. Rights, equity, and justice indicators.** Metrics used to evaluate the design and implementation, and formative, summative, and transformative outcomes of policies, systems, programs, and practices related to CRC Article 24 and related articles should be structured as rights, equity, and justice indicators.<sup>2,8-10</sup>

- Rights indicators use the principles of human rights and articles of the CRC to describe the status of structure, process, and outcome variables related to the status of children.<sup>2,8</sup>
- Equity indicators explicitly move the science of measurement from quantifying disparities to assessing the root causes of disparities and suboptimal child health and well-being, and the capacity of systems to ensure all children can reach optimal outcomes.
- Justice indicators measure the allocation and distribution of finite resources required to advance rights and ensure equity in systems.

**Principle 19. Disaggregation of data.** Rights and equity indicators cannot be based/measured by aggregate data. Data related to practice, systems, policies, and outcomes must be disaggregated to reflect disparities based on geographic, gender, socio-economic, political, cultural, and environmental determinants.

**Principle 20. Metrics of root-cause determinants.** Given the impact of social, economic, political, cultural, and environmental determinants on child health and well-being, health equity indicators must measure these root-cause determinants in the context of formative and summative assessments of all aspects of state, professional, and stakeholder efforts to fulfill the health rights of children.



## Improving Care through Better Communication: Understanding the Benefits

Lilly Damm, MD<sup>1</sup>, Ulrike Leiss, PhD<sup>2</sup>, Ulrike Habeler, MD<sup>3</sup>, and Jochen Ehrich, MD, DCMT (London)<sup>4,5</sup>

Often a pediatric consultation consists of communication between the adults in the room, namely parents and pediatricians, with brief communication with children. What do children learn and feel from this type of consultation—is it empowerment or marginalization? Can we do better?

### The Challenge

Pediatricians spend many hours of their professional lives talking to families, but how much of their time is spent talking to children. Do they really understand their views on the issues being discussed? As mental health-related morbidity increasingly occupies more time of pediatricians, it appears self-evident that pediatricians should be able to effectively communicate with children and be both confident and competent to talk about the “difficult” or “taboo” areas, such as sex, domestic violence, abuse, self-harm, and even death of children with life-limiting conditions. In fact, pediatricians are taught to diagnose and to treat, and they often present a special and spontaneous motivation to offer child care with a high grade of emotional intelligence and social responsibility to their young patients, which had influenced them to become pediatricians. Pediatricians are also closely attached to their patients’ families, showing high empathy and acknowledging the important role of the child’s family during the healing process. Thus, the emotional scenarios concerning nonverbal and verbal communication in child ambulatory and hospital care and other settings are different from adult medicine. Competent pediatricians may no longer consider communication with children as a challenge by itself, believing that they have done it all the time and have learned by experience. In our opinion, this view seems to be wide-spread and may lead to the underestimation of additional skills for the pediatrician. Learning how to communicate with children of all ages and how to exchange adequate information of different cultural backgrounds should become an integral part of the curricula of postgraduate pediatric training. This also includes systematically learning to handle the child’s rights to health, participation of children during health care, and child-friendly health care in the multiperson setting including the child, the different members of the family, and the different caregivers. We will present a series of articles putting elements of the psychosocial and legal scenario into the center of a debate on inadequacy of child health care services. This report, opens the debate on

the central role of communication between children and caregivers.

### The Current Situation in Europe

Professional communication, especially anamnesis and state description between patients and caregivers, always has been an important factor for successful treatment and improved outcome, thus making it an obligatory part of medical education curricula. However, the type of communication will vary with different ages and it certainly changes between various cultures. Most pediatricians, general practitioners, and specialists working with children have received little specialized training on how to communicate with children in a child-friendly and professional way, how to build empowering relationships, and how to handle difficult situations (eg, how to speak with children about serious matters like long-term or life-threatening disease).<sup>1</sup> These tasks may be delegated to psychologists, social workers, nurses, and others, thus marginalizing the role of physicians in the creative process of mutual understanding. This may undermine doctors’ therapeutic competence and lead to patients’ nonadherence to treatment protocols because the different health beliefs and understanding of each other do not match.<sup>2</sup>

Most European children, when asked to describe their role in medical encounters, reported that they felt marginalized during consultations and that they had difficulties expressing their views and answering questions.<sup>3</sup> On one hand, they felt hampered by their parents, who want to protect their child’s engagement and may restrict child participation by interfering in doctor–child interactions, irrespective of their child’s age.<sup>4</sup> On the other hand, the children did not feel sufficiently invited by their physicians to actively express their own wishes and health beliefs. Doctors were described as too busy and seemed to underestimate the child’s ability to express himself or herself. Thus, the child’s contribution was neglected and—if misinformed—not corrected; therefore, the chances to acquire additional valuable information

From the <sup>1</sup>Centre for Public Health, <sup>2</sup>Department of Paediatrics and Adolescent Medicine, and <sup>3</sup>St. Anna Children’s Hospital, Department of Paediatrics and Adolescent Medicine, Medical University of Vienna, Vienna, Austria; <sup>4</sup>European Paediatric Association, Berlin; <sup>5</sup>University Children’s Hospital, Hannover Medical School, Hannover, Germany

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were reduced. Research studies focusing on communication of caregivers with children, not only with their parents, was under-represented until the 1990s and limited to a few countries. Obviously, children experience a consultation differently from their pediatricians; however, children learn quickly from multiple clinical examinations, and their subsequent involvement will depend on the quality of previous child-friendly care.

Untrained medical staff may not be aware of the potentially devastating impact of their routine actions, when being unaware of alternative individual approaches. If the pediatric team has not learned how to handle difficult situations and to build relationships of trust and empowerment for the child, the result will be that pediatricians will talk about difficult children as if they were objects instead of with them as members of a team. Full waiting areas, shortage of members of multidisciplinary teams, and lack of payment for certain services (eg, health education of children and poorly structured organizational and legal settings) may create limitations to the delivery of more child-friendly consultations.

In spite of the above-mentioned challenges, there exists a legal framework for child-appropriate communication; first, the United Nations Convention on the Rights of the Child (UNCRC) of 1989, and second, an approach to “Child-Friendly Healthcare” from the Council of Europe in 2011.

### Communication with the Child as Central to Medical Consultation: How Much Effort and How Much Benefit for Pediatricians and Children?

In the field of general health care, the benefit of successful communication of patients and doctors is well documented.<sup>5</sup> Medical universities have integrated training for professional communication in their curricula.<sup>6,7</sup> Effective doctor–child communication also is a necessary prerequisite for safe medical care. Communication between pediatricians and children is fundamentally different from communication between general practitioners with adults, thus making specific training an indispensable requirement. Stivers<sup>8</sup> showed that a child’s behavior during a consultation depends on the physician’s communication skills, and even simple trifles can substantially influence child–doctor interaction. Bates et al<sup>9</sup> found that the child’s contribution in medical consultations was limited (some 10%) with the medical interaction being dominated by the physician and the parent. Furthermore, Bates et al<sup>4</sup> described that only few parents and pediatricians supported children to express their views (10%). Having little to no substantial interaction, with the

child, or even talking about the child in the third person, can lead to significant problems for doctors. This will require more time and energy to persuade the child in the future, and having a higher risk that the child will refuse further cooperation or potential noncompliance with treatment leading to long-term sequelae in adult life.

Unfortunately, there is a gap between legal regulations on children’s rights to participate in medicine and implementation of these rights into practice. Particularly relevant are Articles 12 and 13 from 54 Articles of UNCRC, 1989. Governments must assure “to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child: the views of the child being given due weight in accordance with the age and maturity of the child...” Communication has to be based on adequate participation and direct interaction with the child. It is often assumed that children can neither understand nor evaluate relevant medical information, and that they do not know about their own best interests and that, therefore, adults must act for them. Doctors and parents use all these arguments to protect children.<sup>10</sup> It has to be understood and accepted that it remains difficult for adults to accept that even young children are able to understand the seriousness of their disease. ■

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## Improving Care through Better Communication: Continuing the Debate

Lilly Damm, MD<sup>1</sup>, Ulrike Leiss, PhD<sup>2</sup>, Ulrike Habeler, MD<sup>3</sup>, and Jochen Ehrich, MD, DCMT (London)<sup>4,5</sup>

This article compliments, “Improving Care through Better Communication: Understanding the Benefits,” by Damm et al (*J Pediatr* 2015;166:1327–1328).

Children’s competence and autonomy develop through direct social personal experience, not only through general developmental age and physical growth. Some of the youngest children can be among the most informed and confident patients if adequately informed. The competence of children depends on the quality of communication with their parents and healthcare providers, and therefore, correlates with the competence of these caregivers to be supportive and generous when delegating knowledge and power to the child.<sup>1</sup> “Children’s decision-making competence is dependent on others’, such as parents and healthcare professionals, attitudes and not only on their own capacity. Lack of competence, however, does not exclude children from the human right to have a say. It should be noted that it is a decision to leave the determination to a parent or healthcare professional.”<sup>2</sup>

Evaluating a child’s competence poses serious challenges and includes the need for pediatric decision aids (**Table I**; available at [www.jpeds.com](http://www.jpeds.com)). Moreover, it is important to assess the competence of the pediatrician (**Table II**; available at [www.jpeds.com](http://www.jpeds.com)). He or she must be able to understand all relevant information, to retain and explain all issues clearly and resolve misunderstandings, to assist children and parents in their informed decision making, and to respect their decisions, putting no undue pressure on them. Along with respect for children’s views and values, the whole healthcare team may have to test and stretch the children’s and their own boundaries to inform and involve the children. A realistic approach is needed that respects the limits of clinical knowledge, skills, and factual understanding of children and of the daunting risks and uncertainties in explaining treatment and science.<sup>1</sup> Children have different concepts of health and disease than adults and institutional regulations (**Table III**; available at [www.jpeds.com](http://www.jpeds.com)), depending mainly on their cognitive, emotional, social, psychological, and physical development (**Figure**; available at [www.jpeds.com](http://www.jpeds.com)).<sup>3</sup> They need time and space to tell their story, and caregivers need special skills to inspire them to do so.

In a study by Horwitz et al,<sup>4</sup> 80% of parents of 4- to 8-year-olds reported having a psychosocial concern worth mentioning to their pediatrician, but only roughly 50% were actually able to have such a discussion. The doctors themselves may have consciously or unconsciously contributed to this hesitancy.

Studies in pediatric primary care have shown that doctors tend to ignore or dismiss the majority of parents’ and children’s hints and disclosures regarding emotional distress.<sup>5</sup> Many pediatricians are aware of health literacy–related problems and the need for good communication with families, but because of time constraints often struggle to implement communication skills learned previously.<sup>6</sup>

### Managing Complex Relationships

When visiting a doctor, children are almost always accompanied by a parent (and sometimes a stepparent); therefore, a complex multiperson relationship (triad) is the norm in the majority of visits. Both parents and children need good communication, each in a special way, which is a sophisticated challenge for all 3 parties. Dulmen et al<sup>7</sup> pointed out that pediatricians need to be aware that both the parent and the child need sufficient space to contribute to the conversation. In addition, siblings, relatives, or other health care professionals also may significantly influence the interaction of this triadic communication. Additional challenges include limited parental health literacy and the need for emotional support for parents and siblings.

The doctor–parent–child interaction is usually dominated by the adult participants and parents, who, regardless of the child’s age, tend to interfere with the doctor–child communication, and who largely advocate a passive role for the child.

Each participant in the pediatric consultation (doctor, child, and parent) brings certain perspectives, assumptions, and experiences to the consultation, all of which may have a bearing on the ability to achieve a partnership. Gabe et al<sup>8</sup> emphasized that this partnership involves some degree of agreement, or at least mutual respect, for the different “agendas” that each of the 3 participants may have. Like adults, children have a right to be told the truth and to be treated with respect and dignity. Children in oncology wards

From the <sup>1</sup>Center for Public Health, <sup>2</sup>Department of Pediatrics and Adolescent Medicine, and <sup>3</sup>St Anna Children’s Hospital, Department of Paediatrics and Adolescent Medicine, Medical University of Vienna, Vienna, Austria; <sup>4</sup>European Paediatric Association, Berlin; and <sup>5</sup>Children’s Hospital, Hannover Medical School, Hannover, Germany

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sometimes deliberately protect their parents by not telling them how much they know or suffer, a behavior similar to that of children with nonmalignant conditions. From this perspective, the refusal of a child to openly discuss health matters in serious conditions has a special meaning and should be respected by the caregivers.

### Benefits of Good Quality Communication

Effective communication can increase diagnostic accuracy, improve patient understanding and adherence to treatment, and enhance the experience of health services and health outcomes.<sup>9</sup> The doctor–patient consultation is the basis for health interventions, regardless of patient age. Building a trusting relationship with a child and adolescent improves information transfer and induces better socialization toward an active autonomous patient role with health literacy. It improves the health status of the child through self-determination and self-efficacy, which in turn has a positive affect of health. Interviewing skills that provide support and help in recognizing problems are associated with increased satisfaction and reduced distress for all persons involved.

Children can be coached to effectively develop their role as a health partner (Table IV; available at [www.jpeds.com](http://www.jpeds.com)). It is possible to enable children to raise concerns, ask questions, accept information, and participate in the creation and troubleshooting of potential problems with the care plan.<sup>10</sup> Levetown et al<sup>10</sup> reported that children coached in this way preferred an active role in their care, expressed better rapport with the physician, and recalled significantly more information about their medication regimen compared with uncoached controls (77% vs 47%, respectively). Physicians also should encourage parents to coach the child to be an effective advocate for his or her own health. Levetown et al<sup>10</sup> also pointed out that the importance of effective communication skills becomes evident when trying to assess and treat a child's subjective symptom (eg, pain). Without the child's input, understanding the nature and severity of the child's pain is difficult, making it nearly impossible to relieve the discomfort effectively and safely.

### Recommendations

Pediatric training should explicitly include communication skills. Effective communication skills can be taught and

learned with minimal additional resources.<sup>9</sup> Howells et al<sup>11</sup> developed the Paediatric Consultation Assessment Tool, an itemized rating scale to rate triadic consultation skills through direct observation. The Paediatric Consultation Assessment Tool allows an individual assessment of child- and parent-oriented communication within 3 or 4 sessions and emphasizes consulting with the children themselves and on information sharing rather than rapport building. Even short periods of training can be effective, through such approaches as motivational interviewing<sup>12</sup> and specialized training in psychosocial topics. Communication training in any curriculum designed to recognize and manage children's psychosocial issues relevant to primary health care settings has been advocated by Wissow et al.<sup>5</sup> Even brief provider training in communication skills can have a positive impact on mental health communication and it may qualify pediatricians for making short-term interventions. According to Wissow et al,<sup>13</sup> training built on providers' existing knowledge of child behavior and development can reduce their feelings of lack of competency and fears of losing control over time.

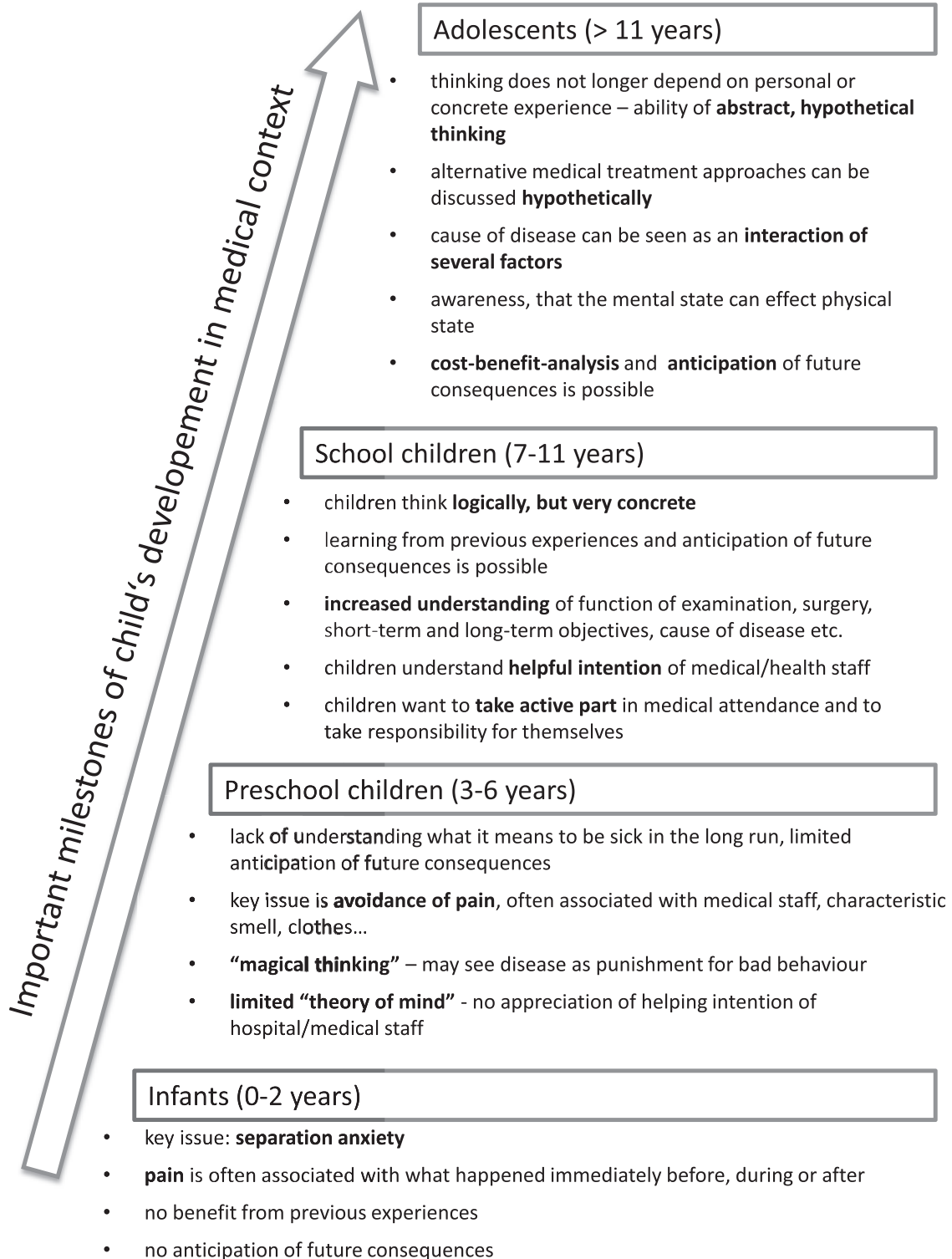
We do not overlook the fact that much more evidence-based information is needed to quantify the positive effect of more active participation of children in communication on treatment outcomes and other variables, such as quality of life, treatment satisfaction, and medium- and long-term effects on child development. There is little doubt that there is a need for well-designed studies to investigate how the partnership with children can actually succeed in practice.

Many questions remain to be answered. To what extent is excellent communication able to shorten the duration of treatment and reduce the number of drugs administered? Is it possible to strengthen health literacy, to decrease the duration of hospital stay, and reduce complications of care? How can education and training in better communication with children and adolescents be developed and harmonized across the various European countries? Implementing existing children's rights to health and concepts like the child-friendly health care model of the Council of Europe into clinical routine are urgently needed to improve the culture of communication between children and their caregivers. ■

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**Figure.** Timeline of child's development in medical context.

**Table I.** How to evaluate the competence of the child in the context of medical care with respect to his or her cognitive, emotional, and social development

	Helpful questions	Examples and practical facts considering the child's development
Competence of the child	<p>Does the child ask his or her own questions and talk about his or her worries independently?</p> <p>Does the child have sufficient knowledge of:</p> <ul style="list-style-type: none"> <li>• Body parts, their position and functioning</li> <li>• Health and disease</li> <li>• Causes of disease</li> <li>• Medical/hospital staff; health care services</li> <li>• Physical examinations and procedures?</li> </ul> <p>Is the child able to learn and benefit from previous experiences related to health care?</p> <p>Is the child able to anticipate future consequences of health care?</p> <p>Is the child able to see and accept the caregiver's point of view and helpful intent?</p> <p>Is the child able to benefit from other children's experience?</p> <p>Is the child/adolescent capable of abstract thinking?</p> <p>Is the child/adolescent able to understand interaction between several factors?</p> <p>Is the child/adolescent able to consider the consequence of different options of health care</p>	<p>Knowledge of body parts and their position can be evaluated verbally or in drawings</p> <p>Owing to "magical thinking," preschool children may see disease as punishment for bad behavior and feel guilty.</p> <p>Infants and preschool-age children often easily remember previous examinations (eg, recognizes how to use a stethoscope), but are not always able to benefit from the previous experience or anticipate future consequences. Their key issue is the avoidance of pain, which is often associated with medical staff, characteristic smells or clothes, or what happened immediately before or after pain; thus, referring to the past or future does not reduce anxiety.</p> <p>Preschool-age children cannot understand and appreciate helpful intention of medical staff because of limited "theory of mind" (to understand that others have beliefs and intentions that are different from one's own); they cannot benefit from other's experiences. Children between about 7 and 11 years think logically, but most of the time very concretely; it is usually difficult for them to understand abstract language (eg, metaphors) and to discuss hypothetical events.</p> <p>Only adolescents can understand roots–cause–effect–outcome models, the life course model, or that the cause of disease can be seen as the interaction of several factors.</p> <p>Not until adolescence can alternative medical treatment approaches be discussed hypothetically (eg, cost–benefit analysis regarding antipyretic drug as a suppository or liquid).</p>
Competence of the family	<p>Did the family prepare the child for the doctor's/hospital visit?</p> <p>How does the family communicate about disease?</p> <p>To what extent do cultural beliefs influence the family's view of health, disease, and medical procedures?</p> <p>Does the family have previous experience with disease?</p>	<p>Using age-appropriate books, toy medical kits, etc</p> <p>Is disease a taboo? Will there be somebody in the family who will speak with the child about his thoughts or worries?</p> <p>What does the family consider as cause of disease - with regard to their cultural beliefs?</p> <p>Is there a close family member of the child suffering from a serious disease? What does the child know about it?</p>



**Table II.** How to evaluate the competence of the pediatrician concerning communication with children

Issue	Pediatrician's competence	Practical examples
Opening	Is the pediatrician able to clear up his function for the child? Is the pediatrician able to involve all participants in the counseling, including the child?	The pediatrician knows the child's name and always talks directly to the child, and not about the child.
Knowledge of child's development	Is the pediatrician competent in evaluating the individual cognitive, social and emotional development of the child • To adapt his or her methods of verbal and nonverbal communication? • To distinguish between when the child should be involved in conversations and decisions and when the child would be overstrained?	In preschool-age children, different concepts of time must be considered. The language of youths should be respected, but not imitated.
Knowledge of child's health beliefs	Is the pediatrician aware of age-dependent health beliefs of the child and the impact of these beliefs on communication?	Children aged 4-6 years often can name only 3 parts of the body, whereas adolescents aged 15-16 years can name 13 parts.
Attitude	Does the pediatrician honestly respect the child's opinion and health beliefs, regardless of the child's age? Does the pediatrician respect the child's opinion and health belief as a positive element in the course of disease or treatment?	The pediatrician does not minimize seemingly irrational fears of the child.
Relationship	Is the pediatrician able to build a trusting relationship with the child to get information about the child's individual health beliefs?	The pediatrician gives full attention to child, listens attentively, and uses direct gaze; encourages child to tell his or her story.
Time and setting	Can the pediatrician provide the time and setting to listen to the child's opinions and health beliefs?	The pediatrician explores the parent's and child's ideas, concerns, feelings, and expectations.
Providing information	Is the pediatrician competent to inform the child about relevant medical facts in an age-appropriate and child-friendly way?	The pediatrician uses age-appropriate language and informational materials; uses online commentary.
Decision making	Does the pediatrician recognize and respect the child's right to resist or refuse (perhaps caused by fear/anxiety)? Does the pediatrician involve the parents and child in shared decision making?	The pediatrician provides time and investment in confidence for other possible interventions if feasible (eg, blood draw). The pediatrician informs the parent and child of alternative evidence-based therapy options, clarifies their benefits and drawbacks, and respects the parent's and child's opinions.
Closure	Does the pediatrician establish and clarify the next steps with the parents and child? Is the pediatrician able to close the session in an encouraging way?	The pediatrician expresses appreciation for the child's cooperation and encouragement to attend the next scheduled visit.

**Table III.** Factors affecting communication with children in health care settings

1. The subjective view (the patient)
  - Patient's own health biography, developmental stages, age, physical growth
2. The objective view (the subjective view of the caregiver based also on his or her own health biography):
  - Knowledge (achieved by education and research)
  - Values (achieved by education)
  - Caring (achieved by empathy, social and clinical skills, and research in public health care services)
  - Technology (achieved by basic, translational, and clinical research and innovation)
3. The interactive view of all
  - Based on open and fruitful communication of all parties involved, mutual understanding, and sharing feelings and values
4. The systemic view (institutions)
  - Regulations (eg, legal aspects, financial factors, organizational limitations, shortage of time)

**Table IV. Transferring theory into practice****Attitude and approach: Prerequisites to speaking with children**

1. Show willingness to enter the child's world to see his or her reality as he or she sees it and to hear his or her fears and losses as he or she feels them.
2. Learn to listen to what the child says and how he or she says it (in both formal settings and unexpected moments). Don't judge his or her opinion, but appreciate his or her thoughts; the child's own concepts of disease should not be underestimated.
3. Create room and openness to give the child a say; try to notice small signals.
4. Enable the child to make competent decisions; provide him or her with the necessary tools.
5. Even if the child is not yet competent to take decisions, he or she still has a right to a say.
6. Improve/enhance communication skills and perceive barriers to effective communication; you will create better outcomes.
7. A support system for staff is necessary: a team culture that acknowledges the emotional impact of such work on staff.

**Routine medical encounters: Recommendations**

1. Speak with the child, not about him or her; do not talk about a child in the "third person" while he or she is present.
2. Consider the child's age-dependent attention span (eg, only 10-15 minutes for 3- to 6-year olds).
3. Improve the likelihood that the child will answer your questions by:
  - Asking social questions early in the visit
  - Phrasing the questions as yes-no questions
  - Directing your gaze at the child during each question.
4. Explain in terms that are appropriate to the child's level of understanding. Use simple language, and avoid complex medical terms and abbreviations; your words may be interpreted very literally.
5. Help the child understand complex procedures through the use of play and/or pictures. Check back with the child about his or her understanding of the previous discussion and ask whether he or she has any new questions.
6. Check with the child about how he or she is feeling, and whether he or she has any specific worries.
7. Outline what is going to happen next, and indicate your availability for further discussion.
8. Three simple communication skills are associated with disclosure of sensitive information:
  - Asking questions about psychosocial issues
  - Making supportive statements
  - Listening attentively. Doctors should not practice multitasking, like writing down notes, having parallel phone calls giving orders to nurses, etc.
9. If a child or adolescent chooses to not discuss the disease despite open information and the opportunity to talk, respect his or her choice.
10. Try to understand that a child who do no longer speaks or communicates with you may have started a journey of no return, and that his or her silence could also mean "protecting parents and siblings."
11. "Let Mum have her say"; manage turn-taking in doctor-parent-child communication.
12. When working with an interpreter make sure the interpreter has an understanding of developmentally appropriate concepts and language for the child.
13. Respect the family's spiritual (even mystic) health beliefs and cultural practices when communicating with the child and the family, but do not follow their track and create new "confusion of thinking."

**Speaking to children about serious matters: Recommendations**

1. Children are interested in health, illness, dying, and death, and they have the right to respect and the truth.
2. Before talking with the child, talk to the parents to give them the information and plan with them how best to talk with their child.
3. Ways that meeting with a child might then proceed: the child together with the parents/primary caregiver; the child without parents, to give the child the chance to discuss subjects that he or she may feel unable to raise in front of their parents; the child/adolescent with another support person, such as a friend or partner; and the child and parents after the parents have talked to the child.
4. Ensure that the setting is appropriate, that is, private, child-friendly, and safe. Arrange to have everyone seated, and if the child is confined to bed, ensure that adults are not standing over the child.
5. Explain in terms that are appropriate to the child's level of understanding: use simple language, avoid complex medical terms and abbreviations, words may be interpreted very literally. Help the child understand complex procedures through the use of play and/or pictures.
6. Ask the child what he or she knows about the illness and/or treatments to date.
7. Check back with the child about his or her understanding of the topics discussed and ask if he or she has any questions.
8. Ask the child how he or she is feeling, and whether he or she has any specific worries.
9. Outline what is going to happen next, and indicate your availability for further discussion.
10. Check with the child about how much he or she wants to know.
11. If a child or adolescent chooses to not discuss the disease despite open information and the opportunity to talk, respect his or her choice.
12. When working with an interpreter, make sure the interpreter has an understanding of developmentally appropriate concepts and language for the child.
13. Respect the family's spiritual beliefs and cultural practices when communicating with the child and family regarding illness and death.

Modified from data in Skeen,<sup>14</sup> Stivers,<sup>15</sup> and Wissow et al<sup>5</sup>.

## Approach to Child-Friendly Health Care—The Council of Europe

Simon Lenton, FRCPCH<sup>1,2</sup>, and Jochen Ehrich, MD, DCMT<sup>1,3</sup>

The Council of Europe was founded in 1949 to defend human rights, parliamentary democracy, and the rule of the law in order to promote a European identity based on shared values across different cultures. It started as 10 nations, but now covers 47 nations, which collectively have a population of 200 million children.

Although the rights of children are well established in the United Nations Convention on the Rights of the Child, Article 24 specifically mentions two elements—the right to the highest attainable standard of health (“the right to health”) and the right of access to health care (“the right to health care”). The challenge has been to translate these principles into practice by developing a comprehensive and consistent model that informs and influences policy making, planning and the delivery, and improvement of services.

Child-Friendly Health Care is the third in a series of reports (which also includes Child-Friendly Social Care, Children’s Participation, and Child-Friendly Justice<sup>1-3</sup>) that form part of the Council of Europe strategy entitled “Building a Europe for and with Children.”<sup>4</sup> The program’s main objective is to help decision-makers and stakeholders protect the rights of children through a practical approach for the provision of services.

### Process

The writing process started in 2009 with a 2-day brainstorming event in Madrid involving a wide range of stakeholders, ranging from parent organizations, professional groups, health service managers, civil servants, and Council of Europe experts, to identify the problems currently affecting the delivery of services for children and families across Europe. After further meetings in Strasbourg, the report entitled “Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care and their explanatory memorandum,”<sup>5</sup> was endorsed by ministers and civil servants representing the 47 nations of Europe by signing the Declaration of Lisbon 2011.<sup>6</sup>

Throughout Europe, the epidemiology of childhood conditions is changing. Admissions to hospital for infectious disease are declining thanks to immunization programs. More children are surviving with significant degrees of disability arising from improvements in neonatal care and specialist care for conditions that would previously have been lethal. There are health-related lifestyles problems, including substance misuse and sexually transmitted diseases. Finally, new morbidities are increasing “diabetes,” mental health problems, attention deficit/hyperactivity, and autistic spectrum disorders. Not all nations are equally affected, but in-

creases in inequity of health are of concern, both within and between nations.

Service response has lagged behind this changing epidemiology. The new morbidities often require interventions, care, and support from a number of different professional groups, often from different sectors simultaneously, and this multi-professional team must come together around the family and deliver a service in community settings rather than in a hospital. This process of transition of service delivery is occurring at different rates in different places and, as a result, there are unacceptable variations in both access and outcomes for children and families. Finally, the knowledge base for systematic improvement is limited by both lack of health services research and a limited adoption of improvement science within the culture of service delivery.

The expert reference group recognized that there are many different systems within the nations of Europe delivering a diversity of health services. Therefore, the child-friendly approach needed to be sufficiently generic, yet sufficiently specific, to enable all systems to adopt and then adapt the model in order to drive improvement within their own systems.

### Key Messages

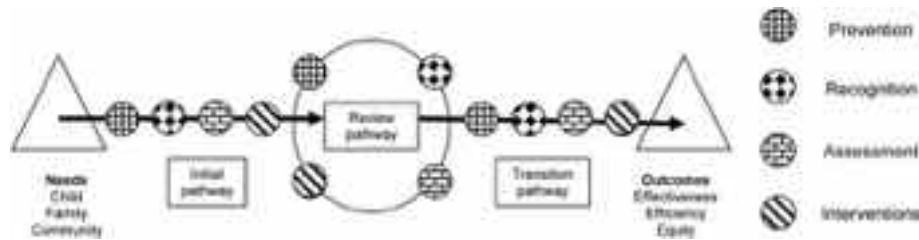
Simply stated, the goal of the child-friendly health care approach is to embed children’s rights to ensure that the right things happen, to the right children, at the right time, in the right place, and using the right staff having the right support, to achieve the right outcomes, all at the right cost. The approach integrates life course pathways to improve health and service pathways to address health problems as they arise.

### Investment in Children is Worthwhile

Children have a right to good health. Promoting the health and the well-being of children brings benefits to society as a whole, both because the antecedents of adult ill-health are often established in childhood (life course epidemiology) and because healthy, happy adults are more able to look after their own children, contribute to society, and provide for an increasingly aging population.

From the <sup>1</sup>European Paediatric Association—Union of National European Paediatric Societies and Associations, Berlin, Germany; <sup>2</sup>Child Health Department, Bath, United Kingdom; and <sup>3</sup>Children’s Hospital, Hannover Medical School, Hannover, Germany  
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**Figure.** Pathway thinking of health care services: illustration of the initial, review, and transition phases, each with four repeating component parts.

## A Whole Systems Approach is Required

A health system is defined by the World Health Organization as “all organisations, people, and actions whose primary intent is to promote, restore, or maintain health.” Its purpose is to “improve health and health equity in ways that are responsive, financially fair, and make the best use of available resources.”

## Prevention Must Be Integrated and Valued

Prevention has many forms—primary prevention includes protection from hazards that have the potential to cause harm and promotion of assets, which contribute to well-being. Secondary prevention identifies conditions; early and tertiary prevention reduces the morbidities associated with the condition. Quaternary prevention reduces the potential for harm from within the health system itself.

## Services Should Be Planned, Delivered, and Improved Based on Pathways

The intention of pathway thinking is to ensure that all the parts are in place and working well together to achieve the desired outcomes. Three types of pathways were identified—an initial pathway covering the development of the condition, a review pathway covering living with the condition, and finally a transition pathway back to normality if the condition is cured, onto adult services, or potentially into palliative care if the condition is fatal (Figure). Each pathway consists of component parts covering prevention, recognition, assessment, and interventions.

## There Must Be Alignment and Synergy between All the Stakeholders to Achieve the Desired Outcomes

In today’s complex world, each component part of the pathway may be delivered by a different professional group, or team, or agency. It is essential that they all work collaboratively and collectively to ensure the best outcomes.

## User Participation Is Essential

User involvement is endorsed at three levels—decision-making for individuals, participation in service improvement, and engagement with policy and priority-setting.

## The Health System Must Be Able to Respond to Changing Conditions, Innovate, and Improve and Learn from Experience

The use of improvement science for measurement, innovation, and learning must become an integral part of service delivery. The intention is to identify and improve the weakest link in the pathway and thereby incrementally improve outcomes.

The child-friendly health care approach is, therefore, a model relevant to the planning, delivery, and improvement of all services. It is universally applicable from a policy level to individual children and their families. The model integrates strategies to improve health and well-being with plans to tackle problems when they occur.

The implications of this approach are that: (1) policymakers, commissioners of services, providers, families, and regulators should adopt the same approach to create alignment and synergy for the greater good; (2) outcomes are only as good as the weakest link in the pathway; therefore, measures reflecting sentinel points in the pathway are required, as well as measures of safety, experience, and outcomes in order to guide where improvement efforts should start; and (3) there must be a shift from targets to a system based on feedback, reflection, and learning through improvement.

Benefits include: (1) reduced waste – “right care – first time” (ie, improved efficiency); (2) improved outcomes “all parts in place and working well” (ie, improved effectiveness); and (3) life-course approaches tackling determinants (ie, reducing inequities and creating sustainability).

## Current Status

Moving from this conceptual approach, based on evidence and consensus, into practical service delivery requires collaboration rather than competition between providers, and multiple steps involving disinvestment in less effective and reinvestment in more effective practice working

simultaneously at a number of different levels. These actions may be “bottom-up” or “top-down,” but the important point must be that all initiatives are in line with one another and always prioritize prevention.

Since publication, further child-friendly initiatives would include an Austrian initiative to increase child participation in decision-making,<sup>7</sup> and the British Association for Community Child Health adaption entitled “The Family-Friendly Framework”<sup>8</sup> in the UK and the Austrian work using pathway approaches to improving cross-border health care.<sup>9</sup>

Recently, the European Academy of Paediatrics, the European Confederation of Primary Care Paediatricians, and the European Paediatric Association agreed to embark on further strategies to encourage implementation of child-friendly health care. ■

*We recognize the contribution of the members of the Council of Europe Expert Working Group on child-friendly health care.*

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# Diversity of Pediatric Workforce and Education in 2012 in Europe: A Need for Unifying Concepts or Accepting Enjoyable Differences?

Jochen H. H. Ehrich, MD, DCMT<sup>1,2</sup>, Alfred Tenore, MD<sup>3,4</sup>, Stefano del Torso, MD<sup>3,5</sup>,  
Massimo Pettoello-Mantovani, MD, PhD<sup>1,6</sup>, Simon Lenton, FRCPC<sup>1,7</sup>, and Zachy Grossman, MD<sup>3,8</sup>

**Objective** To evaluate differences in child health care service delivery in Europe based on comparisons across health care systems active in European nations.

**Study design** A survey involved experts in child health care of 40 national pediatric societies belonging both to European Union and non-European Union member countries. The study investigated which type of health care provider cared for children in 3 different age groups and the pediatric training and education of this workforce.

**Results** In 24 of 36 countries 70%-100% of children (0-5 years) were cared for by primary care pediatricians. In 12 of 36 of countries, general practitioners (GPs) provided health care to more than 60% of young children. The median percentage of children receiving primary health care by pediatricians was 80% in age group 0-5 years, 50% in age group 6-11, and 25% in children >11 years of age. Postgraduate training in pediatrics ranged from 2 to 6 years. A special primary pediatric care track during general training was offered in 52% of the countries. One-quarter (9/40) of the countries reported a steady state of the numbers of pediatricians, and in one-quarter (11/40) the number of pediatricians was increasing; one-half (20/40) of the countries reported a decreasing number of pediatricians, mostly in those where public health was changing from pediatric to GP systems for primary care.

**Conclusions** An assessment on the variations in workforce and pediatric training systems is needed in all European nations, using the best possible evidence to determine the ideal skill mix between pediatricians and GPs. (*J Pediatr* 2015;167:471-6).

See editorial, p 227

From the perspective of understanding how to improve child health care systems, Europe's pediatrics community is unaware of the diversity of provision of primary care offered in 53 different countries and is lacking a comprehensive understanding how this diversity impacts health outcomes.<sup>1</sup> Neither the workforce resources nor the training capacities and confidence in pediatrics are fully understood.<sup>2</sup> After the fall of the Berlin wall in 1990, health care services in general changed in several East European countries from the former Soviet Union system to a Western-orientated structure. After the 2008 financial crisis, many East European countries started discussing changes in existing health care systems, essentially as part of cost containment.<sup>3,4</sup>

Differences in outcome of child health care have been reported constantly for European countries<sup>1</sup>; however, the underlying "root-cause-effect-outcome relationships" are mostly unclear for many diseases.<sup>5</sup> The existing inequalities in the health status of children and adolescents within Europe are unacceptable and therefore should be of common concern to all pediatric societies and, above all, to politicians.<sup>1,6</sup> Unfortunately, the health of children and health care systems for children are seldom discussed by others who are not physicians. In addition, learning across borders about the inequity of child health care services has been hampered by the gap existing between public health research and clinical research as well as by the lack of data.<sup>7</sup> Children and young people often are considered one of the healthiest groups in the population, especially compared with the elderly population, and thereby not viewed as a priority for the health system of country. However, many diseases and conditions of adults and elderly people originate in early life and adoption of the maternal and child health life course model would suggest that investment in services for children would reap benefits in adulthood.<sup>8</sup>

The Strategic Pediatric Alliance (SPA)<sup>9</sup> is a consortium of pediatric associations, societies, and confederations lead by the European Academy of Paediatrics, European Confederation of Primary Care Paediatricians, and the European

From the <sup>1</sup>European Paediatric Association, The Union of National European Paediatric Societies and Associations (EPA-UNEPSA), Berlin, Germany; <sup>2</sup>Children's Hospital, Hannover Medical School, Hannover, Germany; <sup>3</sup>European Academy of Paediatrics (EAP) c/o EAP/UEMS-SP, Brussels, Belgium; <sup>4</sup>California Northstate University College of Medicine, Elk Grove, CA; <sup>5</sup>Studio Vecellio33, ULSS16, Padova, Italy; <sup>6</sup>Institute of Pediatrics, University of Foggia, Foggia, Italy; <sup>7</sup>Child Health Department, Bath, United Kingdom; and <sup>8</sup>Maccabi Health Services, Tel Aviv, Israel

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EPA	European Paediatric Association
EU	European Union
GP	General practitioner
PPC	Primary pediatric care
SPA	Strategic Pediatric Alliance

Paediatric Association (EPA), whose intent is to strengthen the individual efforts of pediatric European professional health care organizations to collectively work more effectively to influence the opinions of governmental administrators, politicians, and relevant European Union (EU) institutions on aspects related to the well-being and services for children. Recent surveys conducted by the SPA have been aimed at identifying the existing pediatric health care systems in 46 European countries, which comprise a population of more than 200 million children. On the basis of analyses of these surveys, SPA aims to improve future services by understanding variations and translating research into practice with a focus on “learning across borders and making a difference.”

The intention of this article is to reveal the spectrum of country profiles on child health and national health care systems and policies concerning age-dependent primary child health care as well as to present information regarding pediatric education and pediatric workforce in Europe as of 2012. The data presented are intended to examine different national approaches to the organization and delivery of child health services and also to provide the basis for comparative analyses.

## Methods

In 2012, a 2-part questionnaire was mailed to the Presidents or leading experts in primary child health care of each of the 42 national pediatric societies belonging both to EU ( $n = 27$ ) and to European non-EU-member countries ( $n = 15$ ). A letter accompanied the questionnaire to explain not only the purpose of the project but also the definitions of specific terms used to assure consistent understanding of what was being asked. Part One of the questionnaire contained questions related to what type of health care provider (pediatrician, general practitioner [GP]/family practitioner, or other) cared for children in the 3 different age groups considered (birth to 5.99 years, 6-11 years, and older than 12 years), and 10 specific questions regarding pediatric education and pediatric workforce (Appendix; available at [www.jpeds.com](http://www.jpeds.com)). Part Two included questions on emerging medical and social conditions related for instance to care of children with chronic medical/health conditions, “new” types of families, and new “minority” immigrant populations. This article will focus on data from Part One.

## Results

Responses to the questionnaire were received from 40 of 42 countries (95% response rate); no data were available from Denmark and Montenegro. Results reported are for these 40 countries unless otherwise specified. Fifty-three percent of countries defined childhood until 18 years of age, 1 country up to 11, 3 up to 14, 4 up to 15, 6 up to 16, and 1 up to 17 years of age. Two countries reported the upper age limit for children in pediatric services to be 19 and 1 country 26 years.

## Delivery of Primary Child Health Care

The proportion of children receiving first access care in 2012 by pediatricians varied according to countries and according to the age of patients (Figure 1). In children aged birth to 5.99 years, two-thirds of the countries (24/36) reported that 70%-100% of children were cared for by primary care pediatricians. One-third (12/36) of countries reported to offer health care to 60%-100% of young children via a GP.

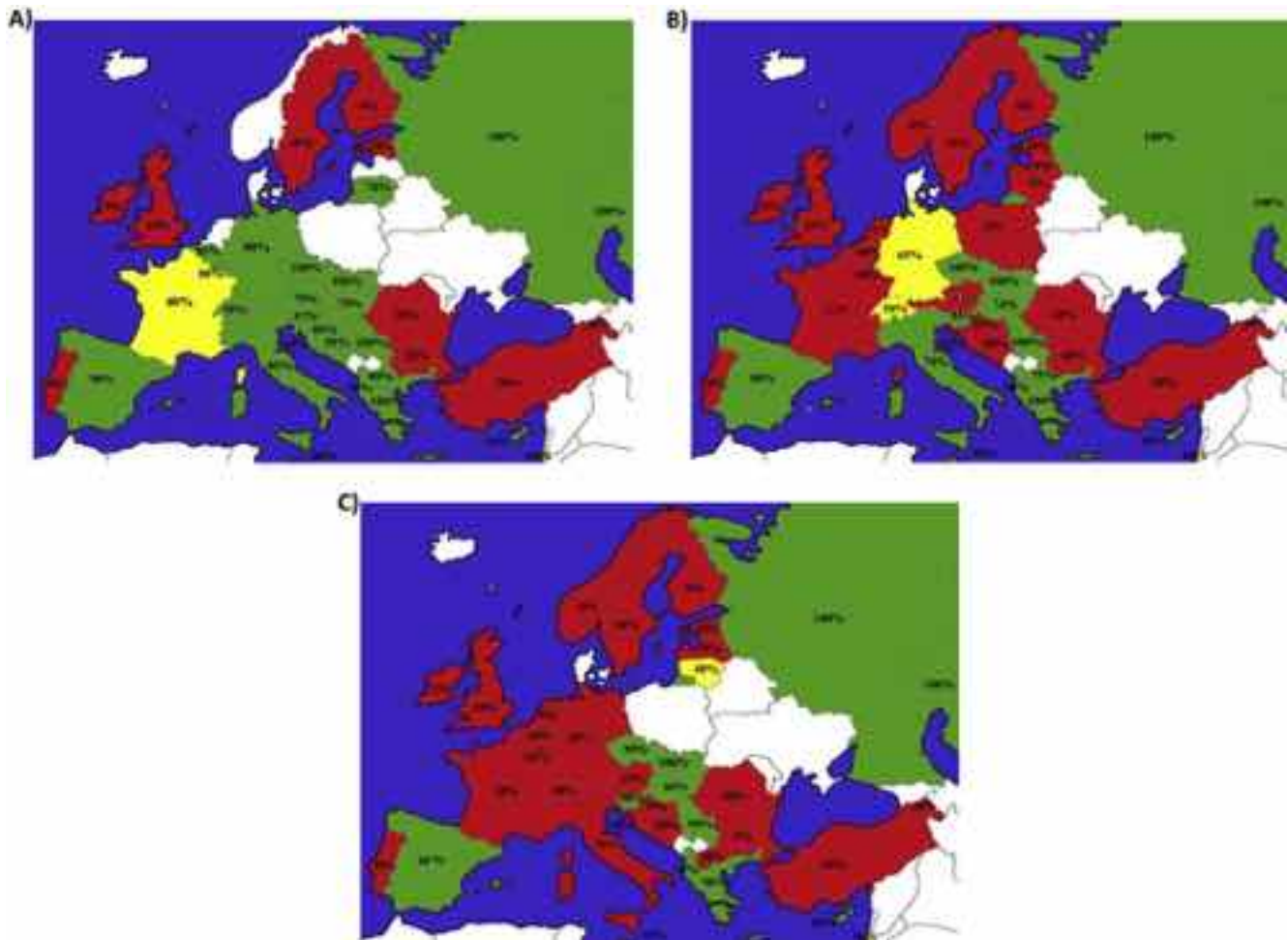
The median percentage of children receiving primary health care by pediatricians declined from 80% in age group 0-5 years to 50% in age group 6-11 years and to 25% in young people 12 years and older. The proportion of children switching from primary care pediatricians to GPs increased with age in one-half of those countries providing a primary pediatric care (PPC) system for infants and preschool children, and in the other one-half of countries the older children kept being followed by pediatricians. Analyzing the proportion of children seen by pediatricians according to the age groups reveals an increasing number of countries reporting an age dependent switch from pediatric to GP care (Figure 2, A and B).

Twelve countries reported to have national discussions of changing from a pediatrician based primary child health care to a GP/family physician based system (Figure 2, C). Different reasons were reported, including economical in 9 countries, political in 6, professional power in 4, historical aspects in 2, and geographical in 1.

## Pediatric Education and Workforce

The number of years in pediatric training to become an accredited pediatrician after graduating from medical school ranged from 2 to 6 years (Table; available at [www.jpeds.com](http://www.jpeds.com)). The majority of countries had a 4- or 5-year training period. Those countries with a 2- or 3-year training period had specialized pediatric faculties that were attended by students from the beginning of their medical studies, which meant that they had undergone more extensive undergraduate training in pediatrics. Trainees in those countries with a 6-year training period had to spend up to a year in a medical-related specialty other than pediatrics. No data are available to answer the question of how many years the trained pediatricians had to spend before or after specialization as a generalist, eg, in remote areas of their country. Thus, the mean age for starting work as a qualified pediatrician could not be analyzed in the different countries.

The recommendation of the Union Européenne des Médecins Spécialistes to have a 3-year common trunk was accepted by 20 of 38 countries; however, it was not possible to give the percentage of national training programs putting the common trunk into practice for individual countries. The median percentage of practical and theoretical training was 70% and 30%, respectively. In-training examinations were reported by 27 of 36 reporting countries. Eleven of 37 countries did not perform a board examination after the full training period. A special PPC track was defined as general pediatric care, first access care, preventive care, health



**Figure 1.** Proportion of children receiving first access care by pediatricians in children ages **A**, 0-5 years, **B**, 6-11 years, and **C**, 12-18 years. *Green*, countries with more than 70% of children seen by pediatricians. *Yellow*, between 30% and 70%. *Red*, less than 30%. *White*, no data available.

education, community care, rehabilitative care, and coordination of all care givers. Such a track in PPC was offered in 52% of the countries. Training in pediatric subspecialty care—such as pediatric cardiology—occurred after the common trunk in 78% of countries and was thus given more often than training in PPC.

Concerning the future pediatric workforce, based on the number of pediatricians being trained and those retiring, one-quarter (9/40) of the countries reported to have a stable number of pediatricians, whereas one-quarter (11/40) reported increased numbers and one-half (20/40) the countries had decreasing numbers of pediatricians, the latter mainly in countries with a change from pediatric to the GP system of PPC. The total number of pediatricians reported ranged from 49 (Luxemburg) to 67 000 (Russia) per country. The ratio of children younger than 15 years of age per one pediatrician ranged from one pediatrician per 408 children to 1 per 11 250 children (mean = 1 per 1707; median = 1 per 1026). The number of annually trained pediatricians per one million child population ranged from 0 to 130 (Figure 3). The annual

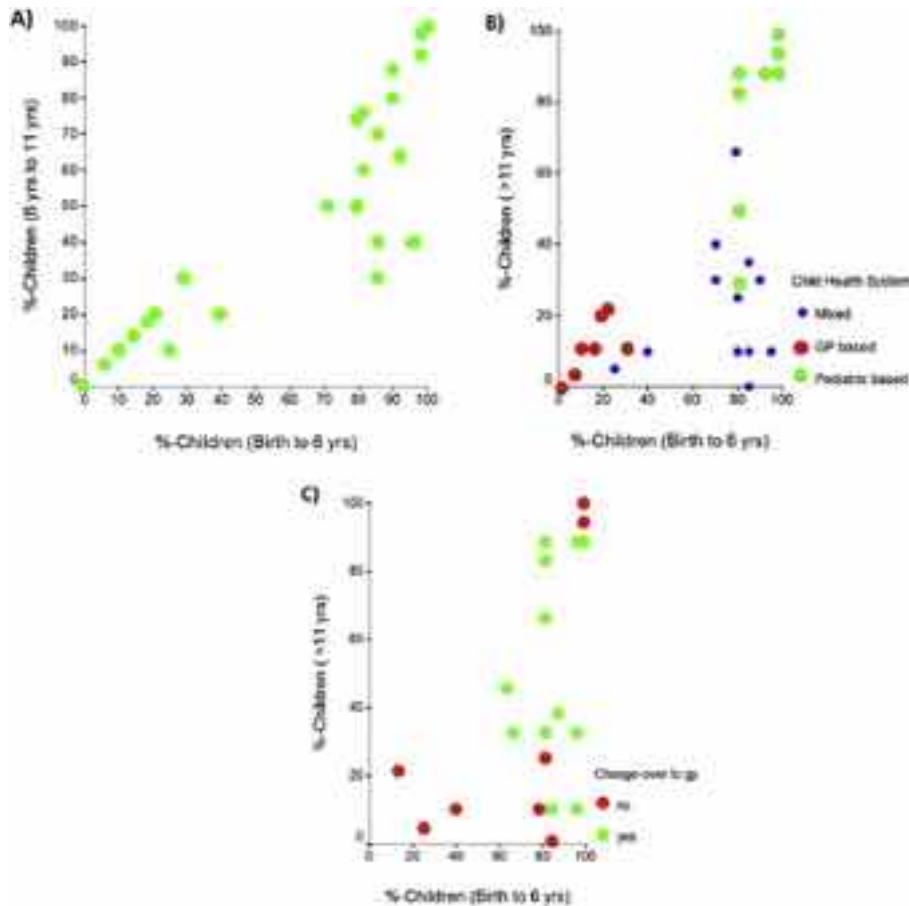
percent of trained pediatricians ranged from 0.5% of all practicing pediatricians to a maximum of 19%. The median annual percentage of newly trained pediatricians was 4.7%.

## Discussion

There is an evidence gap to understand why morbidity and mortality varies across the nations of Europe.<sup>1</sup> The culture of learning across borders was highlighted 20 years ago,<sup>10</sup> and it is unclear whether the expansion of the EU from 15 to 28 member countries will change the situation. Our data support previous findings that there are still very marked differences in child health care systems across European countries. Furthermore, one-half of the countries reported a decrease in numbers of pediatricians and an age-dependent decrease of the proportion of children receiving primary care by pediatricians.

Putting the management of pediatric workforce and its impact on health outcomes for European children at the center of our survey may be criticized because it is not only



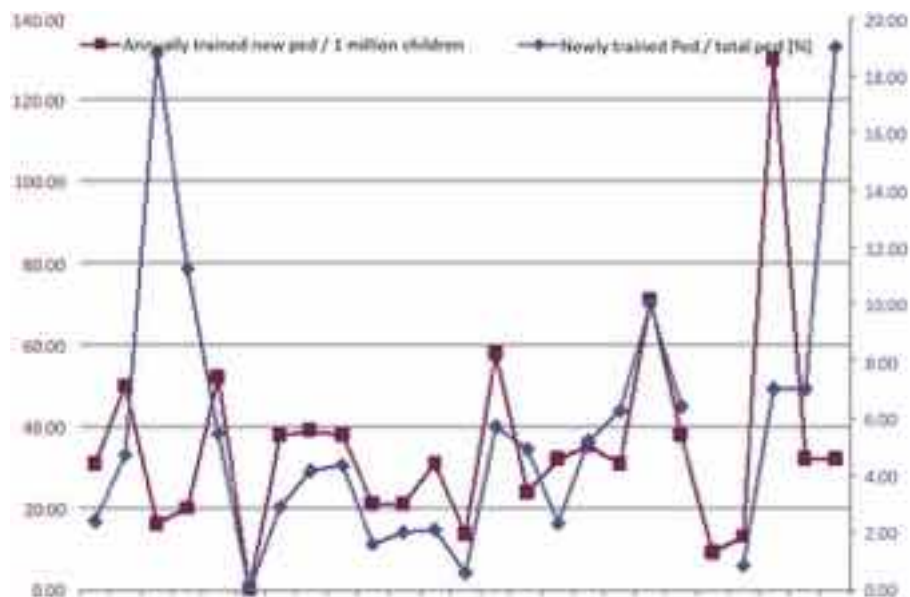


**Figure 2.** **A**, Proportion of children receiving primary care by pediatricians in European countries showing an age-dependent shift to care provided by GPs. Each dot represents at least one country. **B**, Proportion of children receiving primary care by pediatricians in European countries showing a shift to care provided by GPs in 12-18 years old children according to previously defined primary health care systems.<sup>2</sup> **C**, Number of European countries discussing a switch from the pediatric system to the GP system of primary child health care. The **Figure** shows that not only those countries with a low proportion of school children ages 6-11 years receiving medical care by pediatricians will in the future offer primary care by GPs but also those countries with a high rate of PPC in children younger than 6 years of age.

pediatricians but also family physician/GPs and nurse practitioners who deliver primary care for children. Furthermore, there is evidence that multiprofessional teams covering different aspects of primary care may offer better safety, efficiency, and cost effectiveness than the traditional model of uniprofessional practice. In fact, recent data showed that the differentiation of management of PPC into 3 different systems—respectively a pediatric system, a GP/family physician system, and a mixed system with both systems coexisting—no longer reflects the reality of PPC in 2010 in Europe.<sup>1,2,11,12</sup> Although pediatricians and GPs were the main providers of first access care during day-time “office hours” in almost all European countries, multiprofessional teams with nurses were the main providers of emergency care on weekends and in the evening/overnight in 59% of 46 European countries (EPA survey 2009: data unpublished). Preventive care was offered by nurses in 22% of countries, by GPs in 22%, and by pediatricians in 56%. Health care at

schools was offered by nurses in 41% of countries, by pediatricians in 43%, and by GPs in 16% of countries (EPA survey 2009: data unpublished).

This article does not want to contribute to the long-standing discussion in academic literature<sup>2,5</sup> as to who is the preferred physician for treating children in the community but rather to focus on the competencies required for the different elements of PPC. Our data clearly show that younger children were treated more often by pediatricians than by family physicians. Although adolescence medicine has become a subspecialization in some European countries (with accreditation in only one country), there seems to be an ongoing tendency that older children switch from pediatric to GP offices; the question is what age is the most appropriate. This practice will be influenced by national regulations limiting pediatric care to the age of 11 years in one country and to 14-16 years in 13 other countries. However, it also raises the question as to whether pediatricians are sufficiently confident to meet



**Figure 3.** Proportion of number of annually trained pediatricians in relation to 1 million child population and to the total number pediatricians (in %) according to different European countries.

the needs of adolescents whose medical needs are often related to psychosocial disorders and risk-taking behavior. Two of the most worrying findings of our survey were the reported data that pediatric training programs were lacking a specific primary care track in one-half of the countries and subspecialty tracks in one-quarter of reporting countries.

The Presidents of several national pediatric societies reported during a round table workshop in 2009 in Moscow that the mean age of practicing pediatricians had increased in recent years to such an extent that there may be an upcoming shortage of pediatricians within the next 10 years. Our database supports this assumption. The alarming signal is the fact that according to the numbers of newly qualified pediatricians in 2012, there seems to be no improvement in all those countries with a proportion of less than 3% newly trained pediatricians of all practicing pediatricians. Assuming that the mean duration of a pediatric working life is 30 years, there is a need to train 3.3% of all practicing pediatricians each year to maintain a steady state of pediatricians. This calculation does not include factors such as feminization of the workforce, part-time working, early retirement, changing specialties, and immigration, but does clearly indicate that countries with a percentage below 3% will have to rely on migrant pediatricians or on other health care givers, eg, GPs or children's nurses replacing the roles of pediatricians. It is understandable that this conclusion has raised considerable concern among parents and pediatricians.

Thus, the question remains how to develop and provide a sustainable service to children training a workforce that is competent to undertake the care expected of them by families. The principle of a child rights-based approach to health is the requirement that states are deemed subject to progressive realization of the right to health. State obligations fall

into three categories, namely obligations to: (1) respect, which requires states to refrain from interfering directly or indirectly with the right to health; (2) protect, which requires states to prevent third parties from interfering with the right to health; and (3) fulfill, which requires states to adopt appropriate legislative administrative, budgetary, judicial, informational, educational, promotional and other measures to fully realize the right to health.<sup>5</sup>

Children should be considered as a population group in their own right. Changing the existing health care systems merely as a means of cost containment should be discussed in an open, democratic way in society before any action is undertaken by governments or health service planners. There are certainly many more reasons than economic reasons why many European countries have diverging strategies to the organization of their health care systems for children and why they failed recently to standardize their child health care services within the EU and outside the EU according to the new needs.<sup>3,4</sup> Some Eastern European countries had been more or less forced for financial reasons to change their pediatric care system from a former Soviet Union pediatric care concept to a GP system.<sup>3,4</sup> However, the Presidents of national pediatric societies of 6 of these 8 Eastern countries reported to be unsatisfied with the newly created primary health care services for children, which is based upon a GP system (EPA survey 2009: data unpublished).

The Council of Europe guidelines on Child Friendly Health Care<sup>13</sup> proposed an approach to be adopted and adapted locally, that highlighted the importance of implementing best evidence, delivered by competent practitioners working in teams, to ensure all parts of the patient journey through health care systems were present and working well together. Primary care is best delivered by a team with the

experience and expertise to deliver all the constituent parts, which range from preventative care, through to urgent care and the management of long-term conditions.

In conclusion, there is an enormous diversity of child health care offered in European countries which appears to be based not on science but on historical factors. The range and quality care offered by pediatricians is endangered in some European countries. The crisis is not only caused by a switch from a pediatric to a GP health care system but also by a decreasing number of newly trained young pediatricians. It is unclear to what extent this holds true for only primary care pediatricians or also for pediatric subspecialists. There is also a lack of adequate training in primary care pediatrics in some countries; however, this situation seems to be even worse for GPs.<sup>14-16</sup>

Despite an overall decrease of mortality in children younger 14 years of age in Europe there is considerable concern about the fact that some countries did severely worse than others, irrespectively of their Gross National Product.<sup>1</sup> Future research should focus on the question whether this unacceptable variation could be improved by better organization of services and well trained teams of care givers including nurse practitioners, family physicians, and pediatricians, the latter functioning as coordinators of all care givers, and tackling social determinants and reducing inequalities as they have done throughout Scandinavia. ■

*Acknowledgments available at [www.jpeds.com](http://www.jpeds.com)*

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**A. General Information:**

**1) Compiler of Questionnaire:**

Name : \_\_\_\_\_ Country \_\_\_\_\_

Society Represented : \_\_\_\_\_ Position \_\_\_\_\_

Age:	Sex : ♂ <input type="checkbox"/> ♀ <input type="checkbox"/>	N° of yrs in practice;	As a: PC <input type="checkbox"/> Hosp <input type="checkbox"/> Univ <input type="checkbox"/>
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PC: Primary care; Hosp: Hospital based; Univ: University based

**2) Who cares for children in the following age groups and to what extent (approximate %)**

	Pre-schoolers (birth to 6yrs)			pre-adolescence (6 to 11 yrs)			Adolescents (≥ 12 years)			up to what age (yrs) is considered "paediatrics"
	Yes	No	approx %	Yes	No	approx %	Yes	No	approx %	
	Pediatrician:	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	
GP (or FP)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		
Other (specify below*)	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		
*	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		
*	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		

**3)**

If in your country the Primary Care for children is Paediatrician based, is there any talk of a change-over to a General Practitioner/Family Physician - based system?	Yes <input type="checkbox"/>
	No <input type="checkbox"/>

**a)**

If answer to previous question is "Yes", Do you know the reason?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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If above answer is "Yes", does the reason appear to be:

Historical <input type="checkbox"/>	Economical <input type="checkbox"/>	Political <input type="checkbox"/>	Professional power <input type="checkbox"/>	Geographical <input type="checkbox"/>	Other <input type="checkbox"/>
explain as best you can:					

**Appendix.** Part One questionnaire of a survey on child health care in Europe promoted by the SPA among experts of 42 National European Pediatric Societies and Associations. (Continues)

**B: Paediatric Education and Paediatric Work-Force (WF):**

1) How many years is paediatric training in your country?	3yrs <input type="checkbox"/> 4 yrs <input type="checkbox"/> 5 yrs <input type="checkbox"/> ≥6 yrs <input type="checkbox"/>
2) Does your country follow the UEMS-EAP recommendation of a 3yr common trunk?	Yes <input type="checkbox"/> No <input type="checkbox"/>
3) What percent of the training program is:  practical, hands-on work →  and theoretical work →	Practical: %  Theoretical: %
4) Do training programs in your country have In-Training* <b>formative*</b> exams?	Yes <input type="checkbox"/> No <input type="checkbox"/>
5) Do training programs in your country have a Final <u>National</u> <b>summative*</b> exams?	Yes <input type="checkbox"/> No <input type="checkbox"/>
6) Do training programs in your country have a specific "primary care" track?	Yes <input type="checkbox"/> No <input type="checkbox"/>
7) Do training program in your country have "sub-specialty" tracks?	Yes <input type="checkbox"/> No <input type="checkbox"/>
8) Are any paediatric sub-specialties recognized by your Government?  (if "yes", please list them in the section "Additional Comments" under the heading "B8")	Yes <input type="checkbox"/> No <input type="checkbox"/>
9) How many Paediatric physician are formed/year in your country	/yr
10) Based on the Number of paediatricians being formed and retiring each year, what does your country foresee, in the next 15 years, regarding the Paediatric Work Force	Increased <input type="checkbox"/> Decreased <input type="checkbox"/> Stable <input type="checkbox"/>

*\* Refer to following definitions.*

**In-Training examination:** A formative type of examination which serves as a self-evaluation allowing learners to identify strengths and weaknesses in the general knowledge of the specific discipline at the time of the examination and thus enable them to focus their personal study programs and provide direction for future learning.

**Formative assessment:** Assessment used to provide feedback to the trainee about their progress and is aimed at providing insight into their strengths and weaknesses with the objective of improvement

**Summative assessment:** Assessment with the primary purpose of establishing whether or not performance measured at a single defined point in time meets established performance standards, permanently recorded in the form of a grade or score

**Chronic medical/health condition:** any disorder that persists over a long period, is biologically based, requires more than usual access to healthcare services for support and has a significant impact on the life of a person affecting physical, emotional, intellectual, vocational, and social functioning

**ADDITIONAL COMMENTS:**

**(Please print)**

"B 8": If answered "YES", list each (horizontally) separated by "1)", "2)" etc. If "NO" leave next line blank

1) \_\_\_\_\_

2) \_\_\_\_\_

\_\_\_\_\_ Name \_\_\_\_\_ cell phone contact \_\_\_\_\_ e-mail \_\_\_\_\_

**Appendix.** Continued.

**Table.** Duration of pediatric training until accreditation in 38 European countries

Duration of pediatric training (2-6 y)	No. countries (N = 38)	Percentage (100.0%)
2 y	1	2.6%
3 y	1	2.6%
4 y	13	34.2%
5 y	16	42.2%
6 y	7	18.4%

Mercy Health Partners Cholesterol Center  
Cincinnati, Ohio

Reprint requests: Charles J. Glueck, MD, The Cholesterol, Metabolism, and Thrombosis Center, Jewish Hospital of Cincinnati and Mercy Health Partners, Cholesterol Center, Suite 430, 2135 Dana Ave, Cincinnati, OH 45207. E-mail: [cjglueck@mercy.com](mailto:cjglueck@mercy.com)

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# How Do We Create the Best Pediatric Workforce? Questions Abroad and at Home



What is the best system of providing primary care to children and how should pediatricians be trained to maximize health outcomes in children are cogent questions in the changing healthcare environment. Numerous pressures are causing a re-examination of the roles of pediatricians, including the number of children with medically complex conditions or mental health/behavioral conditions, and increase and cost pressures pushing high-cost hospital and emergency room care into primary care settings. Our “system” of primary care for children includes pediatricians, family physicians, osteopaths, nurse practitioners, and others who are distributed randomly and unevenly without coordination.

See related article, p 471

The US is not alone in exploring how best to provide maximal health care for children. In this issue of *The Journal*, a study by the Union of European Paediatric Societies and Association assessed the European child health workforce and the educational background of the pediatrician providers.<sup>1</sup> Responses from 42 European Paediatric Society leaders revealed remarkable variation in the training and distribution of pediatricians as well as the relative composition of pediatricians and family physicians in the pediatric workforce. Among the 42 countries, the ratio of pediatricians ranged from 1 per 408 to 1 per 11 250 children under the age of 15 years. In Europe, as in the US, a greater proportion of children under the age of 5 years receive their primary care from pediatricians compared with family physicians. A dramatic reduction of children receiving primary care after the age of 12 years was observed in Europe. The composition of the primary care child health workforce varied greatly among the European countries. In Russia, 100% of the primary care for children was provided by pediatricians, whereas in Ireland non-pediatricians provided 95%-98% of primary care for children.

The similarity of the structure of the health care systems among the European countries is uncertain and interpretation of their data in the context of the various primary care systems is not discussed by the authors. Information concerning the sex distribution, availability of part-time employment status or the roles of hospitalists or pediatric subspecialists, all factors influencing the pediatric workforce in the US, was not disclosed by the survey. Also unknown is the capacity of primary care across Europe to care for the elderly, as well as children with medically complex and mental health conditions.

The European data provide interesting comparisons with the pediatric workforce in the US. Similar to Europe, pediatricians in the US are distributed unevenly. In 2006, 850 000 children in 47 states lacked any primary care child health provider.<sup>2</sup> An average patient panel for a pediatrician is 1420 children, which is not dissimilar to the mean of 1 pediatrician to 1707 children in the European study.<sup>2</sup> Recent trends have found that more children under the age of 5 years are seeing pediatricians and fewer are seeking care from family physicians.<sup>3</sup> Similar to Europe, family physicians in the US comprise a greater proportion of the primary care workforce for older children, although in the US, pediatricians are seeing an increasing number of children in late childhood.<sup>3</sup>

It is fascinating that 12 European countries were conducting national discussions evaluating a change from a pediatrician-based primary care system to a general practitioner/family physician primary care model. The leading reason for this consideration was economic, although the financial exigencies driving this discussion were not clarified. The high cost of health care is clearly driving changes in the

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practice of pediatrics in the US as well. With the need for more primary care physicians to meet the growing senior citizen population, as well as the increasing number of insured children, adolescents, and young adults, it is unlikely that a similar consideration to reduce primary care pediatricians will occur in the near future in the US. Pressures on health cost care reduction in the US, however, are making significant changes in pediatric health care. Payers are demanding that when possible, medical care for children with complex chronic conditions be redirected from expensive hospital and emergency room care to less expensive primary care settings.

The transformation in pediatric practice is occurring as a rapidly growing interest in pediatric hospital medicine care has emerged. Pediatric hospitalists, pediatric subspecialists, and primary care pediatricians (and other child health providers) increasingly will provide care as an integrated team and receive a bundled payment to distribute across the multiple providers. What this new pediatric health care environment means for the composition of the primary care workforce for our nation's children is uncertain.

The European Study examined training and board certification of pediatricians. Substantial variation in the length of training across Europe was identified. Despite the recommendation of the Union Europeenne des Medecins Specialistes to establish a standard 3-year residency curriculum, only a little more than one-half of the countries responding to the survey have accepted a residency common core curriculum and one-third of the countries did not certify pediatric graduates with a board examination.

Fortunately, in the US, the American Board of Pediatrics and the American Board of Family Medicine continue to offer robust interrogation into cognitive and practical competencies. The coordination of the American Board of Medical Specialties, the Accreditation Council of Graduate Medical Education, The American Osteopathic Association, and the American Association of Colleges Osteopathic Medicine to develop a common certification process will further standardize and verify the competencies of physicians caring for children in the US.

Because of the various levels of pediatric primary care evolving in our country's evolving health care system, it is

reasonable to question whether the current single core pediatric residency training curriculum sufficiently prepares all graduates for their niche within the pediatric workforce. Certainly the adequacy of current pediatric residency training is being questioned by pediatric hospitalists. I posit that the challenges of medical complexity facing primary care pediatricians are equal to or perhaps greater than that facing pediatric hospitalists and may exceed the competencies of the typical pediatric resident graduate. Perhaps greater resident career specialization following a 1- or 2-year core curriculum should be considered to facilitate the increasing complexity in pediatric hospital and community settings.

The most important goal of creating the ideal pediatric workforce is to produce the best health care outcomes for children. The authors of the report from the European Alliance state that outcome measures will be reported in the future. Such efforts are a good beginning. Data evaluating the composition of the collective pediatric primary care workforce, residency curriculum, and pediatric outcomes should determine future workforce planning at home and abroad. ■

**F. Bruder Stapleton, MD**

Department of Pediatrics

University of Washington School of Medicine

Seattle Children's Hospital

Seattle, Washington

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Reprint requests: F. Bruder Stapleton, MD, Department of Pediatrics, University of Washington School of Medicine Seattle Children's, 4800 Sand Point Way, NE RB2 401, Seattle, WA 98105. E-mail: [bruder.stapleton@seattlechildrens.org](mailto:bruder.stapleton@seattlechildrens.org)

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# Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations

Jochen Ehrich, MD, DCMT (London)<sup>1,2</sup>, Massimo Pettoello-Mantovani, MD, PhD<sup>1,3</sup>, Simon Lenton, FRCPC<sup>1,4</sup>, Lilly Damm, MD<sup>5</sup>, and Jeffrey Goldhagen, MD, MPH<sup>6</sup>

The child-friendly health care approach, based on the United Nations Convention on the Rights of the Child (CRC) and endorsed by the Council of Europe,<sup>1</sup> establishes participation of children in their own health care, and in the development of health systems and policies as among the essential elements required to ensure children's access to health care and optimal health outcomes. Evidence from a growing body of European research indicates that children are generally excluded and not sufficiently involved in individual healthcare decisions. This exclusion includes their rights to information (CRC article 17) and the opportunity to express their views and concerns (CRC article 12)<sup>2</sup> in the context of clinical care, service improvement, and policy-making. In addition to the CRC, CRC Optional Protocol 3 speaks to the need for youth to participate in decision making, as do several of the CRC General Comments.

The evidence for poor participation of children in medical decision-making in many European countries is extensive and contradictory. Damm et al<sup>3</sup> reported that a lack of ongoing training of healthcare professionals in communicating with children is an important factor that negatively influences the participation of children. This is despite her associated finding that promoting children's competence in complex decision-making is an essential factor in improving their health.<sup>3</sup> A survey of the European Paediatric Association revealed that in 30 of 35 European countries, chronological age alone was identified as the main criterion for allowing children to participate in decision-making,<sup>4</sup> ignoring the principle of "evolving capacities" promoted in a number of CRC articles. Only five of 35 European countries regarded the developmental stage of competence as the key factor for involving children in decision-making.<sup>4</sup> In the same study, the age limit for seeking children's consent before invasive diagnostic or therapeutic measures ranged between 12 and 18 years. Health education was generally included in school curricula; however, it is unclear if the child's rights to health, participation, equity, and social justice were also included.<sup>5</sup>

The European Paediatric Association survey could not answer the question to what extent the concept of the "ladder of participation" has been implemented into everyday pediatric care. In two-thirds of countries the child's consent was regulated by national law and in one-third of countries by local professional practice. Training regarding access to

information, communication, and participation with children was reported to be rare in most European countries.<sup>4</sup> These and the previous divergent and sometimes contradictory findings indicate that national guidance with respect to youth participation in health venues is based less on science and more on culture and history.<sup>4</sup> They also highlight the spectrum of European countries' translation of the principles and standards of the CRC and children's rights into practice.

## Developing Trust from Mistrust

As all European countries have ratified the CRC, participation of children in society and in health systems is required. Ensuring participation of youth, especially young children, requires knowledge, self-confidence, imagination, and trust on the part of both providers and their pediatric patients. Pediatricians have expert knowledge about disease pathophysiology and treatment options that may be difficult to communicate to parents and children. Also, parents may have their own perspectives that they may superimpose consciously or unconsciously on their children. Children, to the contrary, are often open and receptive to new information and knowledge—regardless of their age. A core principle of child rights is that information must be provided in a language and/or form of communication that is congruent with the child's evolving capacity to understand and respond. Issues may occasionally arise in which parents' perspectives of what is in their child's best interest (CRC article 3) differs from that of the child and/or provider. It is important in these situations to ensure the child has access to information that s/he can understand and process in order for him/her to have an informed voice in decisions that are being made on his/her behalf.

Self-confidence of patients results from positive past experience and can be reinforced with positive feedback. Imagination is an important mental strength to anticipate what is going to happen in the future and, above all, what may be overcome by the child's mental attitude, as used in

From the <sup>1</sup>European Paediatric Association, Berlin, Germany; <sup>2</sup>Children's Hospital, Hannover Medical School, Hannover, Germany; <sup>3</sup>Institute of Pediatrics, University of Foggia, Foggia, Italy; <sup>4</sup>Child Health Department, Bath, United Kingdom; <sup>5</sup>Center for Public Health, Medical University of Vienna, Vienna, Austria; and <sup>6</sup>University of Florida, College of Medicine-Jacksonville, Jacksonville, FL

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cognitive-behavioral therapy. Mistrust based on uncertainty is a healthy reaction towards social contacts; however, it may lead to an unhealthy behavior if it becomes an obstacle in medical care. Medical trustworthiness can be generated through ongoing performance, communication, and empathy of providers.

It is thus important to establish a rights-respecting environment in order to advance open communication and patients' self-confidence, imagination, and trust. The Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services has identified 12 specific rights of children, which, if fulfilled, will help ensure optimal participation of children and do much to advance their self-confidence, nurture their imagination, and maximize their feelings of trust.<sup>5</sup> In addition, the European Association of Children in Hospitals has a charter that should be made available to all children entering into hospitals that describe the rights due to children.<sup>6</sup> Both of these resources are relevant to health systems globally, including the US, despite its status as the only country that has not yet ratified the CRC.

### Rights Holders and Duty Bearers in Relation to Participation

Participation of children in pediatric care means that the child's voice must be heard and opinion respected. It is the responsibility of duty-bearers (eg, physicians, nurses, parents) to ensure the rights of rights-holders (children) are fulfilled. Participation is based on a positive mental attitude of all people involved, and should improve all aspects of health care delivery. If successful, it should generate a new culture of authentic partnership between all involved—including children and adolescents—whose views are required to improve hospital structure and function, as well as processes of medical care, systems development, the generation of health policy, medical education, and research. Participation of children and adolescents in pediatrics also includes developing new strategies for preventing illnesses by addressing risk-taking behaviors and positive health determinants, not only in vulnerable populations but by understanding and addressing the existential vulnerability of all young people. Developing these concepts together with young people to: (1) improve quality of health care; (2) design pathways for translating evidence into practice; and (3) monitor and evaluate patient safety will require focused participatory activities.

Pediatricians must understand and respect the child's right to health.<sup>7</sup> However, they and other caregivers are not the only duty-bearers. Another critical principle of child rights is that with rights come responsibilities. Thus, participation of children in medical decision-making places children in the roles of rights-holders as well as duty- and responsibility-bearers. Improving participation of children in medicine will thus require more than knowledge of their right to health. Empowering children in this sense requires them also to be authentic and collaborative duty-bearers. This process may be positively or negatively influenced by the child's family and physicians.

National pediatric associations and societies should be encouraged to discuss the principles of participation and actively implement, evaluate, and publish initiatives that involve children. Examples include the Austrian working group on "Politische Kindermedizin" ([www.polkm.org](http://www.polkm.org)) who published their articles in Supplement 1 of *Paediatric & Paedologie*,<sup>8</sup> the Royal College of Paediatrics and Child Health and its guidelines for limiting treatment,<sup>9</sup> and the practice of involving children in difficult decisions described by Bagcchi.<sup>10</sup> ■

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# Starting the Debate on the Role of Health Economics to Support Child Friendly Health Care in Europe

Andreas Gerber-Grote, MD<sup>1</sup>, Simon Lenton, FRCPC<sup>2,3</sup>, Volker Amelung, PhD<sup>4,5</sup>, Massimo Pettoello-Mantovani, MD, PhD<sup>3,6</sup>, and Jochen Ehrich, MD, DCMT<sup>3,7</sup>

The Council of Europe produced “Child-Friendly Health Care,” which was endorsed by 47 Ministers of Health during the Declaration held in Lisbon 2011.<sup>1</sup> This health care approach stipulates that sustainable development should fulfill the needs of the present generation without endangering the health of future generations. The aim was to create a virtuous cycle to improve children’s health applying the “5 rights” of protection, prevention, provision, promotion, and participation. However, they did not provide an economic model to support the implementation of the recommendations.

Our aim is to outline the contribution of health economics to the realization of child-friendly health care. The application of classic economic adult health care cost models to child health care is technically difficult because child health care is often more complex and less standardized than adult care (eg, pediatricians are not only treating diseases but the whole child and the family). Up to 8000 rare diseases are the main causes for children with long-term conditions, thus making the use of diagnosis-related group (DRG) systems very difficult to implement. Measures such as quality-adjusted life years (QALYs) developed for adults may be insensitive to the needs of children for a number of reasons, including the lack of appropriate measures and long-term studies.

In summary, there appears to be no role for overly dogmatic economic guidelines in child health, but a high degree of innovation and flexibility is required on which stakeholders in society must agree. The economic models for child health care may have to be adjusted according to different age groups, conditions, settings, and countries.

## Economic Theory and Its Arsenal of Methods

Health economics is the science that describes the factors that influence the production, allocation, and consumption of health care from the perspectives of cost and value.<sup>2</sup> It also includes the analysis of financial and nonfinancial incentives that influence patients’ and physicians’ behavior. Economics recognizes that resources are limited and where there is any scarcity, difficult decisions must be made. Opportunity cost is the term given to the next best alternative to the chosen

option—effectively what you were unable to do because of the choice you made.

This enables health economists to undertake comparative analysis of costs and effects of different resource allocation decisions.<sup>3</sup> Various types of cost and benefit analyses can provide information on how much a new intervention would cost and the benefits in comparison with alternative options. The result is expressed as an incremental cost-effectiveness ratio that holds the difference of costs in the numerator and the difference of effects in the denominator. Outcome can be measured in natural units such as life years gained, cases of prevented diseases or comorbidities, number and severity of reduced side effects, or increased duration and quality of life. Effects also can be displayed as overall measures such as QALYs or disability-adjusted life years. Incremental cost-effectiveness ratios usually are used for decision making on whether to adopt a technology based on its cost-effectiveness that can be compared with an external willingness-to-pay threshold.

In relation to child health care, economic analyses have informed insurance plans, copayments, cost-effectiveness ratios of screening programs, and prophylaxis. The Canadian-based Pediatric Economic Database Evaluation initiative contains over 2600 full economic evaluations published from 1980 to 2013.<sup>4</sup> An overview on methodologic problems can be gathered from the textbook by Ungar et al on child health and economics.<sup>5</sup>

## Major Problems When Applying Health Economics to Child Health

In many health economic analyses, the QALY is used as an outcome measure. The rationale is to fuse gains in life expectancy and alterations in quality of life into one common denominator. Thus, the cost-effectiveness of decisions are comparable across interventions and populations (Figure; available at [www.jpeds.com](http://www.jpeds.com)). A rather strict

DRG	Diagnosis-related group
QALY	Quality-adjusted life year

From the <sup>1</sup>Institute for Quality and Efficiency in Health Care (IQWiG), Köln, Germany; <sup>2</sup>Child Health Department, Bath, United Kingdom; <sup>3</sup>European Paediatric Association (EPA-UNEPSA); <sup>4</sup>Bundesverband Managed Care e.V., Berlin; <sup>5</sup>Institute of Epidemiology, Social Medicine, and Health Care Research, Hannover Medical School, Hannover, Germany; <sup>6</sup>Institute of Pediatrics and Pediatric Residency Program, University of Foggia, Foggia, Italy; and <sup>7</sup>Children’s Hospital, Hannover Medical School, Hannover, Germany

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application of the QALY in the sense that “all gains are equal across a population” may penalize children.<sup>6</sup> Also, these quality of life values—usually referred to as “utilities”—may have to be elicited from proxies, often from parents, rather than directly from the children themselves. There are different ways to remediate these limitations besides not using the QALY at all,<sup>7</sup> which has been the case in some European countries. Nord proposed the saved young life equivalent as a measure that includes distributional and ethical criteria.<sup>8</sup> Also, priority can be given to child health when results from health economic evaluations are compared by putting additional weight on a QALY gained by children.

Another problem particularly virulent in economic analysis of child health is that the time horizon is especially long, particularly with the analysis of preventative interventions such as human papilloma virus vaccinations, and reducing risky life styles such as binge drinking, where the gains will be accrued in a time far into the future. Moreover, nobody can foresee whether future innovative interventions could make our current analysis irrelevant.

A similar issue is raised when choosing discounting values. The underlying concept can be explained as “financial resources gain interest.” These “benefits” may fall into different future years. The same holds for costs. Now, any investor would have to compare expenses and returns from various years to 1 base year in order to select the best investment strategy. Therefore, discounting is applied to make investment strategies comparable. Yet, in child health care, interventions with high costs often have to be paid now, with the effects (the returns on this investment) materializing only in the distant future. With discounting, the future effects will shrink, but the present costs remain in toto.

### The Economic Health Care Model: Cornerstones

Understanding microeconomics provides understanding about how individuals make health-related decisions—whether to buy multivitamins or a better diet. Macroeconomics analyze the entire economy to understand how society makes decisions and distributes resources, including the balance between taxes and benefits, employment, business subsidies, and healthcare spending.

Although basic child health economic models should be applicable across all European countries, resources and costs will vary because of differing investment strategies relating to the determinants of health and the preexisting diversity of child health care service systems.

Effective health economic modeling for children’s care requires: (1) robust and valid data on the status quo and the effect of existing interventions; (2) valid quality and outcome measures, which include mortality, morbidity, and health related quality of life, education achievement, and other outcomes such as the health of the whole family; (3) a health economic framework based on child rights and equity considerations; (4) health insurances and providers amenable

to change; and (5) engagement of politicians and other stakeholders at a national and European level.

### Major Steps to be Taken by Care Providers

Pediatricians and nurses should receive training in public health, health economics, and systems thinking to understand strengths and limitations of health economics and health economic analyses in order to participate in resource allocation decisions.

In 2010, the European Paediatric Association survey revealed that the DRG system was used in 23 out of 46 European countries (unpublished data) and that heads of pediatric departments were involved in managing their departments’ budget in 57% (24 of 42) of European countries. Presidents of national pediatric associations of 37 of 40 countries (90%) affirmed regular concerns from the heads of pediatric departments regarding the infrastructure costs (eg, personnel, diagnostics, therapeutics, investments, supplies) compared with the incomes for their units.

Participation of pediatricians in planning, financing, and decision making should be encouraged in child health care provision. Additional costs related to children compared with adult DRGs, such as hospital school, kindergarten, speech therapists, psychologists, social workers, career advisers, playgrounds, admission of parents, and meals for parents should be included when costing care. The potential of age-adjusted DRGs should be investigated because young children and their families may need extra interventions at different ages.

In order to effectively advocate for children and families, pediatricians in positions of influence within political systems also need to have a good understanding of macroeconomics to reduce the numbers of children and families living in poverty, which has many adverse impacts on health.

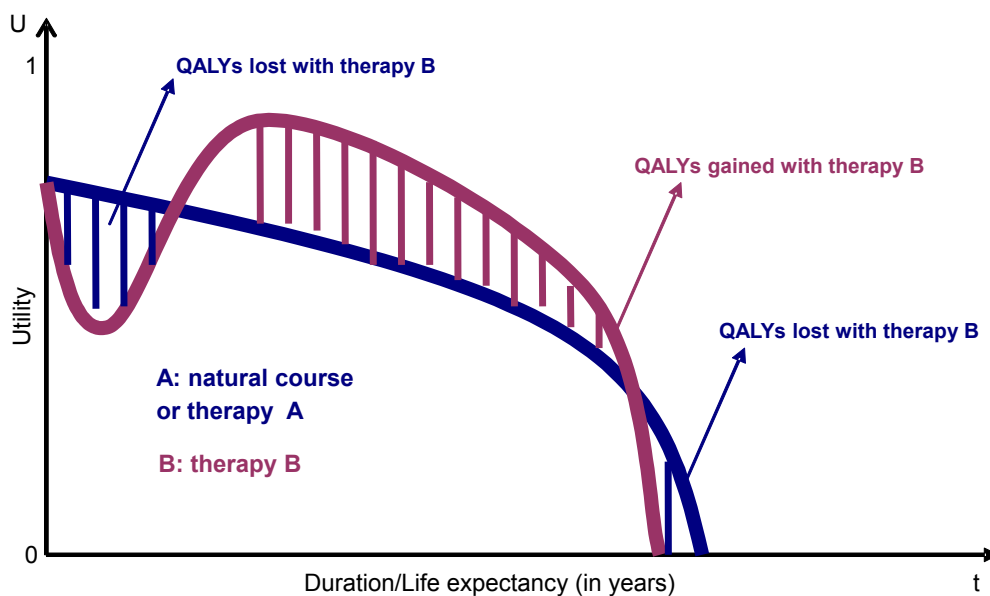
### Conclusions

Health economics is not the enemy of child-friendly health care, which depends, in part, on better investment in the provision of social, environmental, and medical determinants to improve health (Table; available at [www.jpeds.com](http://www.jpeds.com)). Health economics is an emerging science with a considerable relevance to health care in general and in particular child health care. Although some experts debate on the importance of health economic evaluations, all stakeholders must be aware of the strengths and limitations of a health economic approach when making decisions within health economics. Health economics is one of many elements within decision-making, which is particularly important in times of austerities, rationing, and difficult prioritization within health care systems. A simple strategy of avoidance and thus evading a discussion on costs, value, and economic evaluation related to health is no longer tenable. It thus remains an open question how long the value of health economics can be withheld from child health care. ■

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**Figure.** The QALY is a product of quality of life and length of life/life expectancy. QALYs are treated as equal regardless of when they accrue and who wins them.

**Table.** Economic contribution health and well-being of children

**1. Social determinants** (approximately 85% of total costs) to protect children from harm and promote their physical and mental well-being.

Contributors include the state, communities, school and environment, families, and others (eg, the European Union, banks, industry), based upon corporate, personal, and international social responsibility and action.

**2. Health service determinants** (approximately 15% of total costs) to prevent diseases and to provide pediatric care.

Contributions include health promotion programs, screening, immunization, emergency care, etc., based upon transfer of medical and economic knowledge from theory into practice.



# Opening the Debate on Pediatric Subspecialties and Specialist Centers: Opportunities for Better Care or Risks of Care Fragmentation?

Jochen H. H. Ehrich, MD, DCMT<sup>1,2</sup>, Reinhold Kerbl, MD<sup>3,4</sup>, Massimo Pettoello-Mantovani, MD, PhD<sup>1,5</sup>, and Simon Lenton, FRCPC<sup>1,6</sup>

Expert specialist care is essential for the diagnosis of rare conditions and for children who require complex investigations and highly technical interventions, such as transplantation. This intensive specialist care often requires deep collaboration between a number of specialists to ensure optimal outcomes. Generally, how this specialist care is planned, organized, funded, and assured has not been fully researched, thus, the result is a huge diversity of provision across Europe.

Less well-resourced countries in Eastern Europe face the dilemma of how best to develop specialist care in the future, better resourced countries in Western Europe face the problem of how best to rationalize and co-locate interdependent specialist services to improve outcomes, and small countries must find ways of developing effective cross-border care.

Large centers with multiple specialists often are recommended as the best way forward, but this strategy also risks fragmentation and potentially undermines the competence within local hospitals, as well as being inconvenient for families living far away.

We describe the nature of specialist care, the training of specialists, and the interdependencies between specialist teams and propose networked solutions to overcome some of the concerns, such as the increasing gap between primary and tertiary care.<sup>1,2</sup>

## European Pediatric Subspecialties and Training

A questionnaire regarding the accredited pediatric subspecialties was mailed to all the presidents or leading experts in tertiary child healthcare of the 24 national pediatric societies within the European Union (n = 16) and to European non-European Union-member countries (n = 8). The results were then discussed with 35 presidents of national pediatric societies during a round table symposium of the Europaediatrics Congress 2015 in Florence, Italy. Twenty-four European countries reported a total of 38 different accredited pediatric subspecialties in 2014 (Table I; available at [www.jpeds.com](http://www.jpeds.com)) compared with 22 in the US in 2012. The number of accredited pediatric subspecialties per European country ranged from 0-20. Six of 24 countries reported no accreditation of any pediatric subspecialty. The other 18 countries split equally (9 vs 9 countries, respectively) with either 1-7 or 11-20 subspecialties. Eighteen countries reported that

subspecialty training started during the postgraduate pediatric training program irrespective of whether the subspecialty was accredited or not. Six countries offered no subspecialty experience during the 4-5 years of basic pediatric training. More than one-half of the reporting European countries had no accredited subspecialty qualifications.<sup>3</sup>

It also should be analyzed if the career choices meet the needs of subspecialists,<sup>4</sup> and if there are appropriate incentives to become a subspecialist. The training of pediatric scientists in basic, translational, clinical, and healthcare research in the centers must follow guidelines according to the recommendations of European pediatric subspecialty societies.<sup>5</sup> Subspecialty training programs should be vigorously quality assured, and the competence of trainees should be regularly assessed.

More than 30 European pediatric subspecialty societies and associations now exist in Europe (Table II; available at [www.jpeds.com](http://www.jpeds.com)). For example, a 1990 survey from the European Society for Paediatric Nephrology revealed in 1990 that there was an unacceptable variation in delivery of pediatric renal care within Europe.<sup>1</sup> This was related to factors such as size of the population, geography, politics, design of health systems, and financing. These inequities still persist, particularly with regard to access of renal replacement therapy for youngest patients.<sup>6</sup>

## Highly Specialized Pediatric Centers

The concept of centralizing subspecialty care is based on the assumption that centralization will lead to improved quality of care and reduced costs; however, this hypothesis is as yet unproven for most subspecialties. There is some consensus on what needs to exist within specialist centers including a highly competent multidisciplinary team, co-location of interdependent specialists, high-tech diagnostics and therapeutic interventions, and appropriate

From the <sup>1</sup>European Paediatric Association (EPA-UNEPSA), Berlin, Germany; <sup>2</sup>Children's Hospital, Hannover Medical School, Hannover, Germany; <sup>3</sup>Department of Pediatrics and Adolescent Medicine, General Hospital Leoben, Leoben, Austria; <sup>4</sup>Political Pediatric Medicine, Vienna, Austria; <sup>5</sup>Institute of Pediatrics and Pediatric Residency Program, University of Foggia, Foggia, Italy; and <sup>6</sup>Child Health Department, Bath, United Kingdom

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research facilities. There is, however, a paucity of published data on how different pediatric subspecialties have developed<sup>3,7</sup> or, indeed, how they work together. This poses a challenge for healthcare planning and policy makers to improve access to high-quality healthcare services across Europe.

A 2-day international seminar on the role of highly specialized pediatric centers was held in Salzburg, Austria, in 2014 to discuss future provision in Austria, Switzerland, The Netherlands, and Germany<sup>8</sup> with specialist and general pediatricians, public healthcare experts, administrators, politicians, and representatives of a patients' organization for children with rare diseases. The seminar confirmed: (1) the significant differences in highly specialized care across European countries; (2) the absence of consistent definitions of either specialist care or specialist centers; (3) differences in training programs and assessment, both within and between specialists; (4) absent data on the numbers and qualifications of specialists; (5) lack of quality measures relating to competence and service provision; (6) largely no data on numbers in training or future workforce planning; and (7) the difficulties in achieving significant change or reorganization in provision.

The Salzburg seminar focused first on how best to plan an adequate number and the geographical distribution of specialist centers across neighboring regional and national borders,<sup>9</sup> in order to avoid either underprovision or oversupply between centers. Second, it focused on how to develop a sustainable workforce to meet the medical needs of children. Many different factors must be taken into account in this process including geography, population distribution, transport links, relationships between centers, political appetite for change, and engagement with clinicians to name but a few. Critical to the discussion is the number of children requiring highly specialized interventions to maintain the competence of the specialist team within the center. Most families accept traveling long distances to receive specialist investigations or treatment but not for care that could be provided safely by their local health services.

The ideal system that combines the best of both worlds can be summarized with the words "centralized specialization and decision-making, but decentralized provision of treatment whenever possible." From a patient perspective, all the parts are in place and working well together with specialist advice easily accessible, but delivery is as close to home as is safe and sustainable. In this networked solution, all the teams actively collaborate and constantly strive to improve safety and experienced outcomes. The specialist centers should not be seen as "stand-alone" institutions but part of a well managed clinical network that promptly refers the most appropriate children and simultaneously receives children back into the local system for rehabilitation after specialist care. Clinical leadership for specialist care resides with the center, which organizes shared care with clear clinical care plans, with training and joint clinics for local teams. The local team organizes every day care, habilitation liaison with social care, and

education as appropriate or with good 2-way communication with the center. This has already been achieved in some cancer and neonatal networks.<sup>10</sup>

Further research is needed to determine either the optimal size of specialist centers based on the primary outcomes of effectiveness, equity, and efficiency, given different circumstances or the optimal size of population covered by specialist centers. Work has already been undertaken to determine the co-location of pediatric subspecialties (Figure; available at [www.jpeds.com](http://www.jpeds.com)).

The consensus of the Salzburg symposium was that the process should be initiated by political representatives that all stakeholders should be involved with finding solutions, the best options being endorsed by policy or legislation and then change being led by senior clinicians.

Highly specialized pediatric subspecialty care may potentially lead to fragmented care if there is no general pediatrician to oversee the integration of care plans from the perspective of the child and family. As stated by Vohra et al<sup>11</sup>, "pediatric integrative medicine should be the pediatricians' new subspecialty" to bring specialist care together.

## Key Messages

1. Specialist care should focus on the diagnosis and treatment of children with rare and severe diseases to ensure that these children receive the right treatment from the right experts, at the right time and in the right place.
2. Highly specialized teams must collaborate closely with the pediatric teams who refer children and those who then rehabilitate children after complex interventions. There must be clarity over which teams provide what to guarantee comprehensive family friendly healthcare including other comorbidities in the child and the consequences for other family members.
3. Integrating specialist centers into the traditional organizational structures of primary, secondary, and tertiary pediatric care is of utmost importance to avoid fragmentation of pediatric care. A successful network would include centralized management and decision-making by specialized teams with decentralized provision of treatment whenever possible.
4. This networked approach requires good clinical leadership and governance, shared values, common protocols, competent clinicians throughout the network, and collaboration rather than competition between centers.
5. Smaller countries should collaborate with foreign centers. Workforce planning on a pan-European basis is a high priority to prevent either overprovision or underprovision of specialists. ■

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Subspecialty	H-O	CARD	NEPH	META	ENDO	HEPA	OT <sub>1</sub>	CHIR	PICU
Hemat-Oncology (H-O)	Black								
Cardiology (CARD)		Black							
Nephrology (NEPH)			Black	Gray					
Metabolism (META)				Black					
Endocrinology (ENDO)					Black				
Hepatology (HEPA)						Black			
Organ transplantation (OT <sub>1</sub> )							Black		
Pediatric surgery (CHIR)								Black	
Pediatric intensive care unit (PICU)									Black

**Figure.** Necessary co-location of pediatric subspecialties in centers of competence according to their selected competence (eg, a center for organ transplantation should have the following other subspecialties well developed: H-O, CARD, NEPH, META, CHIR, PICU [gray] whereas other subspecialties like ENDO [white] are not required).

**Table I.** Thirty-eight different subspecialties in child healthcare, reported as recognized subspecialties in 24 European countries

	Subspecialty	Number of countries
1	<i>Adolescent medicine</i>	1
2	<i>Allergology</i>	8
3	Anesthesiology	2
4	<i>Cardiology</i>	14
5	Community pediatrics	1
6	<i>Dermatology</i>	2
7	<i>Developmental pediatrics</i>	1
8	<i>Emergency pediatrics</i>	5
9	<i>Endocrinology</i>	13
10	<i>Gastroenterology</i>	13
11	<i>Genetics</i>	2
12	Gynecology	2
13	<i>Hematology</i>	8
14	<i>Hepatology</i>	2
15	<i>Immunology</i>	3
16	<i>Infectious diseases</i>	4
17	<i>Intensive care</i>	9
18	Mental health	1
19	Metabolic diseases	5
20	<i>Neonatology</i>	16
21	<i>Nephrology</i>	12
22	<i>Neurology</i>	14
23	Neurodisability	1
24	Neuropsychiatry	5
25	<i>Oncology</i>	12
26	Ophthalmology	3
27	Orthopedics	2
28	Oto-rhino-laryngology	3
29	Pharmacology	1
30	Palliative pediatrics	1
31	<i>Pneumology</i>	12
32	Primary care pediatrics	5
33	Radiology	3
34	Rehabilitation	3
35	<i>Rheumatology</i>	8
36	Stomatology (dentist)	2
37	Surgery	6
38	Urology	5

Not listed: *Child psychiatry and child abuse.*

In Italics: accredited subspecialties by the American Council of Pediatric Subspecialties. Pediatrics Volume 130, Number 2, August 2012.

**Table II.** Selection of European pediatric subspecialty societies and other pediatric societies that had been active in the last 25 years

1. European Society of Paediatric Infectious Diseases (ESPID)
2. European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)
3. European Society for Cystic Fibrosis (ESCF)
4. European Paediatric Neurology Society (EPNS)
5. European Society for Paediatric Haematology and Immunology (ESPHI)
6. European Society for Paediatric Endocrinology (ESPE)
7. European Society for Paediatric Nephrology (ESPN)
8. European Society for Immunodeficiencies (ESID)
9. European Society of Paediatric Allergy and Clinical Immunology (ESPAI)
10. European Society of Cardiology
11. International Society of Paediatric Oncology (SIOP) European section
12. European Society for Paediatric Research (ESPR)
13. Society for the Study of Inborn Errors of Metabolism
14. Paediatric Rheumatology European Society (PRES)
15. European Society for Social Paediatrics (ESSOP)
16. Club International de Pédiatrie Sociale (CIPS)
17. European Society of Paediatric Intensive Care (ESPIC)
18. Unité multidisciplinaire de santé des adolescents (UMSA)
19. International Federation of Paediatric and Adolescent Gynaecology (FIGIJ)
20. Société Européenne de Pédiatrie Ambulatoire (SEPA)
21. European Association of Children in Hospital (EACH)
22. Association for European Paediatric Cardiology (AEPIC)
23. Association for Paediatric Education in Europe (APEE)
24. European Association of Paediatric Surgical Association (EUPSA)
25. European Society of Developmental Pharmacology
26. Pediatric section of European Society of Human Genetics
27. European Society for Paediatric Urology
28. Pediatric section of European Public Health Association (EUPHA)
29. European Paediatric Surgeons' Association
30. Society for Pediatric Pathology (SPP)
31. European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA)
32. European Association for Palliative Care (EAPC)
33. European Paediatric Formulation Initiative (EUPFI)
34. Association of Paediatric Emergency Medicine (APEM)
35. European Society for Child and Adolescent Psychiatry (ESCAP)
36. Paediatric Nursing Associations of Europe (PNAE)
37. European Union for school and university health and medicine (EUSUHM)
38. European Union Committee of experts on rare diseases (EUCERD)
39. Hospital Organisation of Pedagogues in Europe (HOPE)



# The Economic Burden of Child Maltreatment in High Income Countries

Pietro Ferrara, MD<sup>1,2</sup>, Giovanni Corsello, MD<sup>1,3,4</sup>, Maria Cristina Basile, MD<sup>5</sup>, Luigi Nigri, MD<sup>3,6</sup>, Angelo Campanozzi, MD<sup>1,3,7</sup>, Jochen Ehrich, MD, DCMT<sup>3,8</sup>, and Massimo Pettoello-Mantovani, MD, PhD<sup>1,3,7</sup>

**M**altreatment is a common cause of children's functional and emotional impairment.<sup>1</sup> Costs for the society are high, as a substantial amount of resources have been allocated for various types of services connected to maltreatment of children. These include acute treatment, long-term care, family rehabilitation programs, and judiciary activities.<sup>1,2</sup> There is a long-lasting debate on how child abuse could be prevented or reduced. How can the costs of related services be contained? What is the role of pediatricians in such efforts? This article raises these important questions within the framework of the debate opened by the article by Gerber-Grote et al regarding the role of health economics in improving children's health care.<sup>3</sup>

## Prevalence Rates in High Income Countries

Child maltreatment, also referred to as child abuse and neglect, includes all forms of physical and emotional ill-treatment, sexual abuse, neglect, and exploitation that result in actual or potential harm to the child's health, development, or dignity, specifically in individuals between 0 and 18 years of age.<sup>4</sup> It is estimated that, globally, 1 in 15 individuals under the age of 18 years are subjected to maltreatment annually.<sup>5</sup> The comparison of child maltreatment prevalence rates and related statistics between nations is difficult because of many factors, including different legal frameworks and recording systems. However, it is recognized that this is a largely widespread phenomenon involving approximately 150 million individuals worldwide, in both low and high income countries.<sup>5,6</sup> Considering the latest data from the European Union, maltreatment prevalence rates were reported to be 11.2% and 9.5%, respectively, in United Kingdom and Italy, statistics which are similar compared with data from the US (12.1%) and Canada (9.7%).<sup>7,8</sup> Unfortunately, in many economically developed areas around the world, including the countries of Brazil, Russia, India, and China,<sup>9</sup> statistics on the prevalence of maltreatment in children and adolescents have not been standardized, making reliable cross-national and cross-continental comparisons difficult.<sup>10</sup>

## Costs of Child Maltreatment in High Income Countries

Recent studies and data analyses from different countries have reported that the costs for medical treatments, social rehabilitation programs, justice, and long-term support plans for maltreated children lead to an increase of public

expenses, which could be preventable. Implementation of preventive programs, improvement of medical care quality, and rationalization of health and social services are among the measures suggested to contain the costs.<sup>7,8,11</sup>

Data from the US indicate that child maltreatment represents a serious public health and socioeconomic problem for high income countries.<sup>11</sup> The US Centers for Disease Control and Prevention reported 580 740 cases of child maltreatment in 2011, including fatal (n=1740) and non-fatal cases.<sup>11</sup> The striking economic analysis presented in that report estimated the total financial burden caused by child maltreatment to be approximately \$210 000 over the lifetime for each victim who survives, with a conservative estimated total cost of \$124 billion a year. Such figures include child and adult health care-related costs, child welfare, productivity losses, criminal justice costs, as well as special education, and have been reported to be comparable with the total lifetime costs per individual, related to other important illnesses, such as stroke (\$159 846) and type 2 diabetes (\$181 000-\$253 000).<sup>11</sup>

In Europe, the situation is not dissimilar to the one observed in the US. The average economic and social costs of child maltreatment in Europe were estimated by the European Commission to be approximately 4% of the European countries' gross domestic product (GDP) each year.<sup>12</sup> This figure includes child health care, social welfare, justice, and loss of productivity costs. The *European Report on Preventing Child Maltreatment* estimates that altogether sexual, physical, and mental abuses affect 117 million children under 18 years of age.<sup>12</sup> Furthermore, the report suggests that maltreatment causes about 850 deaths per year in children under the age of 15 years. These figures seem to be an underestimation. This is due to many reasons, including the fact that pediatricians often experience difficulties in recognizing child abuse, mostly because of a lack of proper training in this matter, and to the possibility that they may fail to report child maltreatment because of the social and legal consequences of such diagnosis.<sup>12</sup>

From the <sup>1</sup>Italian Society of Pediatrics (SIP); <sup>2</sup>Institute of Pediatrics, Catholic University Medical School, Rome, Italy; <sup>3</sup>European Paediatric Association-Union of National European Paediatric Societies and Associations (EPA-UNEPSA), Berlin, Germany; <sup>4</sup>Institute of Pediatrics, University of Palermo, Italy; <sup>5</sup>Campus Bio-Medico University Medical School; <sup>6</sup>Italian Federation of Pediatricians (FIMP), Rome; <sup>7</sup>Institute of Pediatrics and Residency program, University of Foggia, Italy; and <sup>8</sup>Children's Hospital, Hannover Medical School, Hannover, Germany

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Of course, socioeconomic costs are different for each type of abuse, and usually reflect the general, social, economic, and health conditions within the states and their local communities, as well as the differences of public health programs among countries in general. Saied-Tessier reported that the total annual cost of child sexual abuse was £3.2 billion in the United Kingdom.<sup>13</sup> This included criminal justice system costs (£149 million), services for children (£124 million), child depression (£1.6 million), child suicide and self-harm (£1.9 million), adult mental and physical health care (£178 million), and loss of productivity (£2.7 million).<sup>13</sup> In Germany, childhood trauma as a consequence of abuse was also reported to be a relevant economic problem, and the trauma follow-up costs were estimated to be in the range of €11.1 billion to €29.8 billion, approximately €134.8 and €363.5, respectively, apiece for the German population.<sup>14</sup>

A recent study by Bocconi University, based on the official data reported in 2010 by the Italian Ministry of Health, investigated the overall costs of child abuse for the Italian Public Health system.<sup>7,15</sup> The study reported a total of 100 231 maltreated children in Italy, and the costs related to maltreatment to be €13.1 billion per year, including direct and indirect costs. Direct costs included hospitalization (€49.6 million), mental health care (€21 million), welfare, facilities, and residential services (€163.8 million), foster care (€12.6 million), professional social work (€38 million), and juvenile justice (€53.4 million). Indirect costs included child special education (€209.8 million), adult and juvenile crime (€690.4 million), adult health care (€326.1 million), and loss of productivity (€6.6 billion). In summary, for each victim, Italy spends approximately €130 259, and each year the new cases of child maltreatment have a total cost of €910 million.

### Contrasting Child Maltreatment

As healthcare costs continue to skyrocket, prevention programs are considered a correct cost-effective approach for contrasting child maltreatment.<sup>16,17</sup> In fact, economic analyses have demonstrated the value and the cost-effectiveness under limited resources of preventive services because the costs incurred as a result of the services provided divided by the health outcomes achieved had a favorable balance.<sup>17-19</sup>

Prevention of child maltreatment should become a priority within child health programs worldwide. Public health preventive interventions in this area should include the strengthening or development of health care services adequate to deal with child maltreatment, and training programs for health care personnel, including pediatricians during their residency period. In particular, it has been suggested that preventive programs should put particular focus on risk factors.<sup>6</sup> These include poverty, large families with low income, poor parenting social and communication skills, early parenting, parental mental health problems, parental drugs and alcohol abuse, parents who were themselves abused or neglected during childhood, domestic violence, social isolation, and marginalization.<sup>6</sup>

Effective prevention programs for child maltreatment are based on close interactions between State institutions, such

as Public Health, Education, and Law, and should be supported by appropriate public information programs, which can play an indisputable role in raising awareness of child maltreatment. Accurate information on the positive role of prevention programs on long-term costs and outcomes is important to help such programs make their case to civil society and policy makers.

### Conclusions

Child maltreatment has a serious socioeconomic impact on society in Europe and other parts of the world.<sup>6</sup> It has been demonstrated that victims develop negative outcomes, such as mental and physical health problems and behavior disorders, such as anxiety, depression, and suicidal ideation. Furthermore, destructive interpersonal relationships and delinquency were also frequent findings in these subjects.<sup>6</sup> The currently available analyses show that the high long-term costs that are related to maltreatment during childhood represent a major economic challenge, which expands its impact with a long time horizon by involving various areas of child and adult health care and the social system in general, including hospitalization, mental health services, child welfare, education, socioeconomic productivity, and justice.<sup>7,15</sup>

Among the 28 European Union countries, there are concerns regarding the financial resources allocated to preventive public social services, as it has been shown that the effectiveness of such services in the European Union is significantly influenced by insufficient funding.<sup>20</sup> In particular, a study on national policies by the European Commission has recently emphasized the absence of specific recommendations regarding children services and the scarcity of preventive programs, which are modestly supported by the member states, and insufficient for breaking the cycle of disadvantages.<sup>21</sup> In such perspective, there is a real risk that insufficient investment in prevention will increase future demand for child health and care services when the overriding challenge is to reduce it.<sup>22</sup>

Contrasting child maltreatment has both strong ethical and economic implications, and raising attention on this phenomenon is a contribution to the debate recently opened on how to develop proper economic models aimed at improving children's health, within the frame of the "5 rights" of protection, prevention, provision, promotion, and participation emphasized by the Council of Europe.<sup>3</sup> ■

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Corresponding author: Pietro Ferrara, MD, Institute of Pediatrics, Catholic University Medical School, Rome, Italy. E-mail: [p.ferrara@unicampus.it](mailto:p.ferrara@unicampus.it), [pferrara@rm.unicatt.it](mailto:pferrara@rm.unicatt.it) (P.F.)

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