



European Academy of Paediatrics  
U.E.M.S. - Section of Paediatrics - European Union of Medical Specialists

## **Strategic Paediatric Alliance**

**A joint statement from  
European Academy of Paediatrics (EAP)  
European Confederation of Primary Care Paediatricians (ECPCP)  
European Paediatric Association (EPA)**

# ***A shared approach to Improve community and primary care services for children, adolescents and their families in Europe***

**Draft statement for consideration by signatories**

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**20 Aug. 2015 Version 13**

**Intended readership**

Professional groups involved with the planning and delivery of primary/community services for children and families. Particularly for those experts involved with future strategies and their respective partners in the resource distribution parts of health systems, namely those people with policy/planning/commissioning roles. This paper is also relevant for those involved with workforce planning, training and assessment and quality improvement.

**Foreword**

This joint statement has been prepared in response to increasing concerns about the quality of services provided for children and families in community settings across Europe. These concerns are driven by three main factors - variations in outcomes, which include both morbidity and mortality, inequities of provision, both within and between nations and the difficulties with recruitment, training and retention of an appropriately trained and competent workforce, which includes paediatricians, family doctors, general practitioners, children's nurses and other professional groups.

This paper intends to be equally relevant to improve GP-based, paediatrician based and mixed systems of primary/community care in Europe. The long-standing categorical debate, often accompanied by entrenched positions, about whether General Practitioner or Primary-Care Paediatrician based primary-care offers the best way forward, is unhelpful as both options have strengths and weaknesses. In addition some countries have mixed models of primary/community care and not merely the two simple categories as the debate might suggest.

Whilst it may be self-evident that better trained clinicians will offer higher quality care, this needs to be considered in the context of limited resources (both financial and workforce) and the requirement to create best value within the overall health economy. This will include a debate about the proportion of resources to tackle the determinants of health, in order to promote well-being outside the health service and consequently health service demand, as well as the resources to manage ill-health within a health service.

## Purpose

The purpose of this paper is to ensure that any future changes to the organisation or provision of services, benefit children, young people and their families. At the very least any future changes should improve health, improve the outcomes of services, improve the experience of services, reduce unnecessary variations and inequalities and be sustainable. Additionally services should be safe, provided as close to home, enable children and young people to participate in their own health care and balance prevention with provision.

***This paper outlines the issues that need to be considered when discussing a strategy to improve primary/community based services for children and families. The intention is not to describe one single model that is equally appropriate across Europe, but rather to provide policymakers and practitioners a framework to enable appropriate evidence-based decision-making for the benefit of children and families.***

## Principles

Article 24 of the UN Convention on the Rights of the Child enshrines the rights of children to both health and health care. In terms of health service delivery the Convention can be distilled into five fundamental *principles* (reference Council of Europe Child Friendly Health Care). These include the **participation** of children and families in individual decision-making, participation in service improvement and participation in policy related matters, **protection** from all forms of hazards that have the potential to cause harm, **promotion** of assets that have the potential to create health and well-being and finally access to high-quality **provision** based on pathways, which integrates **prevention** at every level.

To ensure good outcomes all the component parts of a pathway, which contribute to the 'patient journey' through services, should be in place and working well together - this is integrated care in practice. These component parts should all be based on best evidence, delivered by competent providers, in the right place and at the right time. This simple system should then be accompanied by meaningful measures which enable the providers to learn and improve their system through incremental innovation.

## Introduction

The terms primary, secondary and tertiary care are now outdated and it can be argued that they have now become potential obstacles to improving communication, cooperation and integration of care between different teams who provide care for families. The terms are probably best substituted by community, hospital and specialist centre care, which merely describes where the care is provided. Planning and provision based on pathways enables the component parts to be clearly identified and then the teams involved to work together, to create integrated care from the perspective of children and families.

***This paper only considers those services provided outside hospital or specialist centres, meaning those in community settings.***

Community delivered care includes:

- Urgent and emergency care with referral systems for potentially life-threatening conditions - which includes medical, surgical and psychiatric conditions.
- The management of undifferentiated concerns presenting to the 'first contact practitioner' -effectively triage and initial management.
- The provision of "preventative" services which range from health surveillance, the delivery of screening programmes and immunisation.
- Caring for vulnerable children including safeguarding roles
- Some public health programmes delivered at the community level such as injury prevention.
- Care for children with long-term conditions which include medical, psychological, social and practical care; sometimes called 'chronic care'.

- Some “tertiary (specialist) care” which does not require the high tech environment of a specialist care centre.

What is very evident from experience is that the health care system must be seen as a "whole", because, when making changes in one part of the system there are often unexpected consequences in other parts of the system. Increasingly the term "integration" is being used to describe how all parts of the system should work together.

Governments often do not recognize the large returns on investment by making child and adolescent health a priority area. However those involved with providing services should also recognise that resources are limited and must be used wisely to achieve the maximum benefit for children and families.

***The improvements required in community-based services will be different in different nations, so each nation will have to review provision, based on the issues highlighted in this paper, before making any substantial changes.***

### **Variations in primary care**

There are significant variations across Europe in the way that primary and community child health services are financed, organised, delivered, quality assured and improved. There is often little quantitative evidence to support one system more than another, but there are often strong opinions advocating one option over another. While some examples of best practice have been published and replicated, lack of health services research currently limits the spread and adoption of effective improvements. This work is too often limited by poor access to relevant data and information from existing health service information systems, many of which have often been designed to support business functions rather than quality assurance and improvement functions.

The variations that must be considered when planning or improving future services include:

- ***The age of transition*** from paediatric/child health services to adult services. Currently this transfer from paediatric primary care to general practitioner care may range from 5 to 18 years. In some countries the transition may be up to 24 years for those young people who may otherwise become "lost in transition" namely those with rare long-term conditions, significant mental health problems and ongoing disabilities, particularly where there are poorly developed adult services for this age group. The age of transition significantly alters both the numbers and competencies required of the workforce involved.
- ***All care should be as evidence-based*** as possible and the access to and the quality of care across Europe should not depend upon how the health system is organised or financed.
- Evidence-based care should be ***delivered by a competent workforce*** working in teams that collaborate to provide a responsive and comprehensive service for the local population they serve.
- Different nations in Europe organise care in different ways and this is particularly relevant for the care of children with long-term conditions, those with mental health conditions and those where there are safeguarding (child abuse) concerns. As a number of long-term conditions become more ***prevalent the workforce must evolve to maintain their competence*** with relevant continuous professional development (CPD) and continuous medical education (CME) over their working lives.
- Services may be delivered from an office, health centre or polyclinic, with some services also being provided in preschool settings, primary and secondary schools or colleges. ***Services should be provided as close to home*** as possible in appropriate environments for the care being delivered.
- Some primary care services operate "office hours" whereas others provide 24/7 services. If a 24/7 service is not available then alternative "out of hours" services will then be required to ensure that hospital emergency departments are used appropriately when community services are unavailable. The challenge is how to ***maintain a consistent high quality paediatric service 24/7*** throughout the year.
- In some health systems preventive care is provided within a "public health service" organised separately from primary care, likewise in some systems all "specialist care" is provided only in hospital settings. ***It is essential to plan services using a "whole system approach"***.

One specific issue is the overlap of competencies between different professional groups. For example, the role of primary care paediatricians compared to family doctors in providing health care to children and young people. Each

have both a unique skill set and also a common skill set and the challenge for future provision is to ensure children and young people have access to the right mix of competencies, in the right place and at the right time and that **individuals work in teams who all collaborate within integrated networks**, all striving to continuously improve the care they provide. All professional groups including family doctors and general practitioners require appropriate paediatric training to be competent in their clinical work.

### **Changing morbidity**

Mortality throughout childhood has dramatically reduced, especially for the younger age groups, over the last century. There has been a shift from infectious diseases in younger children to the new chronic/long-term conditions/morbidities in older children as more children now survive acute illness and injury and are surviving longer, but sometimes with ongoing disabilities.

Changes in society have resulted in increased numbers of children with obesity, mental health problems and there is increasing recognition of all forms of child maltreatment particularly neglect.

Risk-taking behaviour during adolescence may pose a threat to health particularly alcohol, substance misuse and sexually transmitted diseases. Death and other consequences of accidents are still a significant problem in many countries of Europe. It is essential that the local workforce is competent in all these clinical areas

Migration within Europe and migration to Europe particularly from North Africa is having a significant impact on baseline numbers within populations for which health services are planned. Additionally some migrants have significant health problems associated with their countries of origin and new morbidities associated with the difficulties they experience when integrating into new cultures.

Throughout Europe inequalities between and within nations continue to increase, particularly in times of austerity. There is great historic diversity in both welfare support for families, employment opportunities and levels of investment in health care between different nations. Regardless of political system social solidarity is increasingly being eroded by weakened regulation which no longer guarantees human rights to health. These concerns are particularly relevant to migrants and children of refugees who experience difficulties accessing high quality health care in many countries.

### **Changing use, expectations and technology**

Expectations of health services are ever increasing and consultation rates are generally rising rather than falling over time. Access to information via the Internet often increases uncertainty and anxiety, thus increasing consultation rates particularly within the first contact, urgent and emergency care part of the health care system.

Despite the "digital age" a significant number of records, predominantly in Eastern Europe, are still paper-based and where electronic records exist, they rarely work seamlessly to support communication between community, hospital and specialist centres, nor between health, education and social care; neither do they often provide data-based information that supports quality improvement.

The potential for "e-consultation" using e-mail, texts, videoconference and other social media has yet to be fully explored, although the potential for electronic monitoring of everything from calorie intake, physiological measurements and other behaviour is rapidly expanding with the development of smart phones and wireless devices. Using this technology will be an important part in improving the quality of care particularly for long-term conditions where significant lifestyle changes are essential.

### **A skilled workforce**

The dilemmas behind the guaranteeing a competent team to manage the full range of problems presenting in community settings and primary care are considerable. First, there must be clarity about what care is expected to be provided, then the roles of different professional groups within "primary care" have to be clearly defined in terms of their competencies (based on knowledge, attitudes and skills).

There has never been agreement on the question of "which professional group does what", nor the training or assessment required to become competent. Therefore, in some nations paediatricians are responsible for all the community delivered care, whereas in some other nations preventative services are delivered by nurses (including children's nurses and public health nurses), undifferentiated concerns managed by family doctors and nurse practitioners, specialist care by paediatricians and mental health from a variety of professions within mental health providers of services.

The workforce challenge is to ensure appropriate access to a range of professionals who work together efficiently and effectively in a team and who can comprehensively meet the range of needs within their local population. The health team for children and families may include paediatricians, general practitioners, family physicians, children's nurses, psychologists and psychiatrists, physiotherapists and many others. The interfaces between other agencies for example education and social care and adult services will require further definition of roles and responsibilities and agreement on how the teams work together.

The total workforce must be competent both clinically and culturally to cover their local population and additionally be able to assure and improve their services using appropriate improvement science methodologies.

In many places the current total workforce capacity is insufficient to provide a comprehensive service for a variety of reasons. Sometimes it is insufficient numbers in training to replace retirements, sometimes inadequate resources, sometimes inadequate training, sometimes a lack of system design and leadership.

In specific countries there has been a proactive policy decision to replace primary care paediatricians with general practitioners/family doctors, whereas in others a passive strategy to train inadequate numbers of paediatricians thus resulting in substitution by default. A similar dilemma is the balance between paediatricians providing mental health care and the professional groups within child and adolescent mental health services. Increasingly paediatricians are being expected to provide more mental health provision, sometimes without the necessary training and support to do so. It is essential that children and families have access to well-trained and competent doctors to meet all their medical needs. It is intended that this paper enables discussions that will create clarity about roles and responsibilities so that, in turn, better workforce planning follows.

Any proposed change to primary/community provision of services must be evaluated from a whole system perspective, for example, substitution of well-trained paediatricians by less well-trained general practitioners may result in lower quality care and more onward referrals resulting in higher overall costs within the system over time. On the other hand, when there are insufficient numbers of paediatricians or general practitioners, their roles and responsibilities should be reviewed to discover whether some of their duties could be delegated to other professional groups, providing they are equally competent, to deliver that element of their role and quality of care will not suffer.

A particular issue for paediatrics and child health is the large proportion of women within the medical and nursing workforce. Enabling parents to balance child rearing and professional responsibilities is a priority if their professional skills are to be retained throughout their working lives. Rarely is there a sustainable workforce plan covering recruitment, retention, ongoing training and retirement for each professional group involved. The concept of "portfolio careers" requires further exploration so, for example, when night time work becomes too arduous alternatives should be available.

## **Conclusions**

The traditional pyramid of public health, primary, secondary and tertiary care is no longer fit for the 21st century and the planning of services for children and families should be child and family focused so based on pathways of care, delivered by teams collaborating networks; with the place of delivery being as close to home as is safe and sustainable to achieve.

Primary care is no longer a single service delivered by a sole practitioner and the new complexities of children's conditions coupled with the impact on their families should be recognised and defined in order to guarantee a competent local team or a multi-disciplinary group practice to manage the range of problems presenting to primary and community services within that local population.

Children live in families and their health often depends on the health and well-being of their parents; this is particularly true for the most vulnerable in society and therefore community services for children cannot be seen in complete isolation from adult services for parents. This is essential for child mistreatment and safeguarding services and is often true for child mental health problems, which may be a reflection of family dysfunction, such as domestic violence and adult mental health problems.

At present there are no data to support one single model of primary care or community service provision that is equally efficient, effective and equitable in all circumstances. To create equity of outcomes will require different models of service delivery in different places, for example urban versus rural, deprived versus affluent, stable versus migrant communities.

Developing a competent team of professionals with the necessary skills and competencies appropriate for local circumstances is essential for improving the quality of care and outcomes for children and families. The team structure must fit with local circumstances and the existing workforce.

To achieve the concept of a "competent local team" it is essential to define what needs to be done, the competencies required and the best model of service delivery. Existing workforce capacity can then be reviewed in the light of these priorities and planning for future workforce numbers and training/retraining can be started.

New models of service delivery require active ongoing research and evaluation in order to determine what works best, in which circumstances and to inform improvement priorities.

The leadership capacity required to review existing community provision, engage with stakeholders and propose new ways of working should not be underestimated, but without such proactive leadership and planning many services for children will fragment and fail to meet their needs in the future. Community/primary care is the bedrock of health service provision and if provided well could significantly reduce unnecessary and often relatively expensive consultations in hospital and specialist centres.

## Recommendations

Each nation in Europe faces a different set of challenges to enable improvement of their primary/community care for children and families. These recommendations are therefore not universal but are intended to create a framework for discussion prior to deciding local or national priorities and action. ***Systems where there is good evidence that they are currently working well should not be substantially altered, accepting the fact that there is always room for incremental improvement.***

## Investment, priority and quality

Any reconfiguration/transformation of services currently described as "primary" or "community" care must offer better quality of care for children and families in the future than currently exists. Generally investments in services for children and families have greater long term benefits for society than equivalent investments in adult or elderly care.

- The quality of care including access, experience/satisfaction and outcomes should not be substantially different depending on cultural factors such as ethnicity, ability to pay, gender or the financial systems operating in any nation.
- Quality of care also includes the safety perspective. Safety covers making the right decisions first time, avoiding "near misses" and adverse events and learning from them when they do occur.
- Quality of care is hugely dependent on the quality of the workforce. It is essential that any future workforce configurations both preserve and enhance the quality of care provided by the range of professionals within the team.
- Investment in "improvement science" and research throughout health services to enable the system to evolve in the right direction is vital.

## Whole system impact

The impact of any changes in primary/community services must:

- Be considered in the wider context of provision of health services for children and families i.e. public health services, community services, hospital services and specialist care in order to mitigate any negative or unexpected consequences.
- Consider the impact on services provided by other agencies for children and families, for example, social care and education.
- Include the views of all relevant stakeholders, including children and families, those providing services, those planning services and those responsible for quality and regulation of services.

## Service needs assessment

Provision should be based on well-defined local needs (defined as the ability to benefit from services), which includes knowledge about:

- age/structure of the local population clearly defining the ages of children included or excluded,
- the mortality and morbidity within the local population,
- a comparison with local health service capacity to meet the identified needs.

## Evidence-based (what works)

Services must be based on the highest levels of evidence balancing effectiveness, efficiency, equity (in relationship to both access and outcomes) and safety to create whole system value. Evidence includes:

- clinical decision-making,
- service and workforce configurations and
- policy development and decision-making.

Where clear evidence does not exist, the knowledge and experience of various stakeholders must be sought and included in the decision-making process.

## Competent workforce



The competence and capacity of professionals providing future services in community settings is of the highest priority.

- **Workforce numbers**
  - Training - sufficient numbers entering training programs to replace lifetime loss in that profession.
  - Retention - ensuring a living wage, good working conditions and access to continuing professional development.
  - Retirement - reducing the causes for early retirement and creating opportunities for portfolio careers.
- **Workforce capacity**
  - Part-time working - enabling part-time working rather than loss from the workforce.
  - Sabbaticals - enabling retraining, where appropriate, in order to keep pace with changing morbidity.
  - Childcare responsibilities -enabling parents with children to maintain their competencies during periods of absence.
- **Workforce competence**
  - Professional and cultural,
  - Improvement science and research
  - Leadership
  - Practical value for children and families

### **General training and competency assessment**

Competence requires excellent initial training, ongoing professional development and continuous application of learning based on innovation and improvement. Training must include:

- Knowledge relevant to expected roles in community settings.
- Skills to apply knowledge in practice.
- Assessment to demonstrate competence in the real world.

Following on from needs assessment the roles and responsibilities of different professional groups should be defined and training programmes for those involved reviewed to ensure that the team is competent to manage the range of condition/morbidities within the population/community.

### **Professional training**

Structured and accountable training programmes are strongly advocated for all practitioners/clinicians/doctors providing primary/community care for children and families,so this will include therapists, nurses and doctors. This training must be comprehensive and cover all aspects of care for which they are responsible. **The training and assessment for specific roles should be equivalent regardless of which professional group the individual clinician belongs, so they are** equally competent to deliver that element of care for neonates, infants, children and adolescents.

When paediatricians are the first- contact provider they would be responsible for provision of comprehensive and continuing care throughout infancy, childhood and adolescence (<19 years) and possibly longer for those people with complex health needs. They should be actively supported by adult health teams when parental health issues adversely affect the health of their children.

When family doctors and nurses provide primary/community health care for children and young people (<19 years) and families they should be effectively supported through an active collaboration with paediatricians and other professional groups with more expertise in order to provide a comprehensive local service for children and families in their area.

All competencies must be maintained and where necessary developed further, as roles evolve and change throughout working lives, to enable the development of high quality teams dedicated to constant improvement in experience and are outcomes.

### **Appropriate setting**

Future services should be delivered in convenient child and family settings either at home or as close to home as is safe and sustainable, within available local resources.

- Child friendly, for example, access to safe play, information to improve participation in decision-making.
- Clinical settings must be fit for purpose.
- Clinicians should have access to appropriate investigations and support services.
- There should be administrative and informatics support for service delivery.

### **Protection, promotion and prevention**

The health and well-being of children depends on both protection from hazards and promotion of assets in their lives to achieve the best life course outcomes.

- The impact of living conditions, lifestyles and the health of parents and other key caregivers must be considered and addressed simultaneously when redesigning health services.
- Prevention of secondary disability from a primary condition must be integrated throughout service delivery.
- Services must be designed to be safe and not cause additional harm, like injuries or infections, when treating patients.

### **Timeliness of referral and access to services**

Children are constantly growing and developing and early access to effective interventions has a disproportionate benefit because children take their health gains with them. Children with acute conditions may deteriorate rapidly. For many conditions outcomes improve with earlier intervention.

- Review access to urgent and emergency services in office and out of office working hours.
- Review access to effective teams for disabled children and those with long term conditions.
- Review provision of child and adolescent mental health services, particularly those young people aged 16-24 years.

### **Learning through improvement**

Any changes in provision should be accompanied by a robust and proportionate process of evaluation to enable "learning from the process of change". All healthcare systems must be able to demonstrate their quality and value and where this evidence does not currently exist, this capacity should be built into new forms of provision.

- Review the structure and capacity for health services improvement and where needed embed improvement science within service provision.
- Integrate innovation and improvement into service delivery at all levels, particularly within networks.
- Ensure staff have access to appropriate continuing professional development to develop or maintain their improvement science competence.
- Invest in national and pan-European structures to encourage "learning across borders" in order to implement best practice.
- Review the capacity of current information systems to provide relevant information which will drive quality improvement.

Our collective aspiration is that children of families have easy and equitable access to effective health services, all parts of which closely collaborate to ensure the best possible experience and outcomes. This vision requires services to be based on the highest quality of evidence, delivered by competent teams who constantly strive for improvement and are supported by a health care system in which there is alignment and synergy between all the stakeholders.

At a practical level, each local community will have a team of professionals who work predominantly with children and their families; they will all have clear roles and responsibilities and function as a team to provide a comprehensive service to meet the identified needs, in ways that are most suitable for their local communities.

Achieving change in established systems always proves challenging and requires leadership, change management and improvement science all working together, but often what works best are examples of good practice to inspire and emulate.

The European Academy of Paediatrics (EAP), European Confederation of Primary Care Paediatricians (ECPCP) and European Paediatric Association, Union of National European Paediatric Societies and Associations (EPA-UNEPSA) are all committed to work with policymakers, service planners, other professional groups and users of services to explore all options and disseminate best practice for the benefit of children and families.

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