Advocating for children’s health: a US and UK perspective

In this article we describe the differing American and British approaches to child health advocacy by paediatricians and paediatric organisations. In the USA, advocacy has a long history and is well established as an important function of the American Academy of Pediatrics (AAP), but the USA still has to achieve universal health care coverage for children. In contrast, the UK has had universal health care for children for more than 50 years and individual paediatricians have spoken out for children. However the Royal College of Paediatrics and Child Health (RCPCH) adopted advocacy as a goal only in 1997.

In our article we pose the following questions:

- What is advocacy and why is it a task for paediatricians?
- In what ways can paediatricians act as advocates for their patients?
- How do advocacy activities by paediatric organisations benefit child health?
- What should be the focus of collaborative advocacy between US and British paediatricians?

What is advocacy?

The Oxford Dictionary defines the verb advocate as “plead or raise one’s voice in favour of; to defend or recommend publicly”; in other words to stand beside, not to do for. Promoting action to effect change for children is a key component of advocacy. Generally child health advocacy efforts begin with an individual patient and may extend into local, regional, or national work in a public health capacity. Advocacy means making a commitment to support the child and family beyond the issues related to the treatment of their individual medical condition. Furthermore, the basis for advocacy is our wish to meet all of a child’s health related needs within the context of family and community. We recognise that factors outside the realm of direct health care provision often inhibit children’s ability to achieve their full potential—particularly among children from disadvantaged families. Examples of such opportunities for advocacy include a child with otitis media who lives in an overcrowded, damp house; a child with a disability who is in a mainstream school but falling behind, being bullied, and receiving inadequate teaching support; or a child with asthma whose teachers are reluctant to provide medication within the school setting.

In looking at the role of advocacy in the UK and the USA the issue of access to care is very important. The origins of the American Academy of Pediatrics lie in the opposition in 1922 of the American Medical Association’s (AMA) Section of Pediatrics to the concept of the federal government developing a small maternal and child health programme—that is, a national programme of health care. This led to a conflict between the paediatricians and the AMA leadership and in 1929, a group of paediatricians met and concluded that a national paediatric society was needed to create “a united front to influence paediatrics in its various phases: sociologic, hygienic, educational, investigative, and clinical”. British paediatricians have never as a group opposed government funded health care and so advocacy to support population based health care has not been required. Perhaps this early experience politicised American paediatricians to become more overtly involved in advocacy and lobbying, while in the UK this role has been carried out behind the scenes and in a less “political” fashion.

In the 1860s, Job Lewis Smith, who is considered by some as a founder of American paediatrics, was a strong advocate for child health. Among Smith’s many advocacy issues was the high death rate of abandoned, illegitimate infants who were not breast fed. Because of his efforts, wet nurses were made available, significantly lowering the morbidity and mortality of these “foundlings”.

Since 1985, the AAP Section on Community Pediatrics has recognised Smith’s advocacy efforts by presenting an annual award to a community paediatrician who has made significant contributions to child health through a community advocacy effort.

In the UK, Donald Court, following in the footsteps of Sir James Spence, was a staunch advocate on behalf of parents and children. He was asked by the government in the 1970s to advise on how to bring together the disparate strands of children’s health services in the hospital and community. The resulting report, Fit for the Future was seminal in developing the UK’s current integrated structures. Court laid particular emphasis on the role of parents, and they were represented on the committee—a first for the UK. One of the parent representatives was Lady Jean Lovell-Davies and she commented as follows: “I would never have got round to making any contribution at all if Donald had not gone out of his way to ask what each parent representative thought at important moments in the discussion. He gave me the courage to speak and the belief that my views and the views of all children and their families were important.”

In what ways can paediatricians advocate for their patients?

Murray Katcher, a paediatrician from Madison, Wisconsin, decided that he had taken care of too many children with hot water burns. On researching the issue, he found that, by simply lowering the temperature at which hot water heaters are set, less children would suffer serious water burns. To that end, Katcher worked with the Wisconsin Chapter of the AAP and the AAP national office to develop model legislation that would mandate lowering water heater temperature settings. Eventually a public education campaign was launched to lower the setting of older water heaters. Thus, all American children gained benefit because of the concern of a few.

In April 2000, the RCPCH awarded the James Spence Medal (its highest award) to Hugh Jackson for his work in child injury prevention. Early in his career in Newcastle-upon-Tyne in the 1960s, Jackson encountered a child who had taken 10 imipramine tablets prescribed for his mother’s depression. Despite all the efforts of paediatricians and cardiologists, the child developed severe fits and arrhythmia, and died within 24 hours. The mother said, “nobody told me it could do any harm”. Jackson, shocked over this failure, conducted a survey into the circumstances of accidental poisoning, published in 1968, and later became a member of the national committee on poisoning, which set up a protocol test team for developing childproof medication containers. This lead to the development of
legislation requiring that certain medicines be dispensed only in these containers, and hence the saving of many hundreds of children’s lives.

The specific steps of paediatrician advocacy shown here include:

- Identifying a preventable problem in one child
- Helping that child to overcome the problem
- Drawing conclusions in relation to the factors that led to the problem in the first place
- Identifying the means to tackle these factors
- Influencing government or policy makers to change/ reform the system that fostered these factors or introduce appropriate legislation (this may require coalition building).

However, it is absolutely not the case that advocacy must lead to national action: very often action at a local level may be quite sufficient.

How do advocacy activities by paediatric organisations benefit child health?

Paediatrics as a specialty brings a support to child health that no other professional can bring. The concept that “one paediatrician can make a difference” is very important, but the 55,000 US paediatricians and 5000 UK paediatricians are often an unrecognised collective leadership and force. The approach taken by the two organisations has been rather different, reflecting their different origins and constituencies. In the UK, paediatricians work at secondary level in hospital or community seeing children referred by doctors or nurses practising at primary care level. Virtually all paediatricians work in the state funded National Health Service. In the USA most paediatricians work in private practice at primary care level seeing parents and children as a general practitioner would in the UK. The UK is a signatory to the UN Convention on the Rights of the Child, while the USA is one of two countries in the world that has yet to ratify the Convention.

As a national organisation, the AAP has adopted a three level approach to advocacy. Through its Washington, DC office, the Academy supports specific national legislation that can improve child health. Over the past several years, for example, the AAP has advocated for universal access to care, improved quality of care, paediatric residency education, immunisations, and gun control, to name a few. Working with many other national organisations, the AAP has learned that coalitions are an effective way to accomplish advocacy efforts.

At state level, the Academy has developed model legislation on issues such as child death review, bicycle safety, immunisations, and paediatric emergency services. This enables paediatricians to interface and educate their colleagues, local politicians, and legislators about child health issues.

The foundation of child health advocacy in the USA, however, begins at the community level. The AAP, via its Department of Community Pediatrics, is “dedicated to and promotes the optimal health of all children by supporting paediatrician participation in community health initiatives”. The Community Access to Child Health Program (CATCH), is made up of volunteer paediatricians whose vision is “that every child in every community has a medical home and other needed services to reach optimal health and well-being”. CATCH supports paediatricians in integrating clinical practice with public health concepts by providing educational and networking opportunities, technical assistance over grant writing, and small grants (up to $10,000) to support the planning of a community based child health programme. The Community Pediatric Department has several other programmes supporting issues such as breast feeding, healthy child care, and children with special needs.

The advocacy role of the RCPCH has been recently developed but is now an integral part of its strategy. The Advocacy Committee was set up at the instigation of Professor David Baum, then College President, following a motion that was passed unanimously at the 1997 annual meeting. The Committee’s initial areas of focus included promoting breast feeding, developing the College’s response to the government enquiry into inequalities in child health, and collaborating with other organisations including the National Children’s Bureau in the development of a national multiagency advocacy network on child health (CHANT). A paediatrician’s guide to advocacy has been published, and a patient and carer liaison group was established to advise and inform Council on the views of children and their families and promote the rights of patients and carers. Guidelines have been written on the health of refugee children.

The College is supporting the implementation of the UN Convention on the Rights of the Child and through its representation on CHANT is raising funds for a worker to support Article 24 of the Convention. The College also works in collaboration with a number of other advocacy organisations such as the UK Working Group on Landmines and Save the Children, working with the latter to raise the age limit for child soldiers from 15 to 18 years. In paediatric training (for which the RCPCH has responsibility in the UK) the College is now exploring how to include a children’s rights perspective in the training of senior house officers. In the international field, the College is following the example of such early pioneers as Cicely Williams and David Morley in setting up a task force for paediatrician involvement in war and emergencies as well as assisting in medical training in developing countries.

Some of the areas of activity carried out by the AAP are not required in the UK because of its universal health care system and primary care teams: for example, every child in the UK has a “medical home” through their GP and health visitor or school nurse. Some of the work of CATCH programmes would be carried out in the UK by statutory services or by initiatives such as Sure Start and Health Action Zones, though these are less likely to involve paediatricians. The added value of paediatrician involvement in such programmes is an issue for debate. We support this role, recognising that primary prevention in child health requires community involvement, and such preventive activities should be integral to the work of paediatricians.

What should be the focus of collaborative advocacy between American and British paediatricians?

There is considerable scope for collaboration between our sister organisations. The Americans have strength in resources and have developed their advocacy role over many years, but have still to achieve universal health care coverage; the British have come to advocacy in an organisational sense more recently but with a strong commitment to interagency working and to bringing about fundamental improvement in child health through government action. The UK has a National Health Service and is a signatory to the UN Convention on the Rights of the Child, and the College may use these as foundations for improving children’s health care. Considering the strengths of both organisations and our shared commitment to promoting children’s health and well being, we believe in the scope for collaboration.

In late 2000, representatives from the RCPCH and the AAP met in the UK to develop a plan for collaborative advocacy with a focus on inequity and the education of paediatricians.
In both the USA and the UK, children are our communities’ most valuable—and vulnerable—resource. Yet they are not always well served by the private sector, institutions, or the government. Collaborative paediatric advocacy on their behalf can enhance their status, their well being, and their health.

We are grateful for comments on this paper from Dr Margaret Lynch, Dr Hugh Jackson, and Dr Mary Rudolf, and for editorial advice from Ms Crystal Milazzo.

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Parental smoking

There can be few people who believe that parental smoking is not harmful to children’s health. Maternal smoking in pregnancy is a cause of poor intrauterine growth and the exposure of children to environmental tobacco smoke increases their risk of otitis media and respiratory symptoms.

Data from the US Third National Health and Nutrition Examination Survey (NHANES III) of 1988–94 (David M Mannino and colleagues. Archives of Pediatrics and Adolescent Medicine 2001;155:36–41) have been used to compare non-smoking 4–16 year old children in successive tertiles for serum cotinine concentration. Children in the top tertile, compared with those in the bottom tertile, had significantly more wheezing, school absence, and impairment of lung function. In children aged 4–6 years high cotinine was associated with a greater likelihood of a diagnosis of asthma.

So what are we going to do about it? In California (Eliseo J Pérez-Stable and colleagues. Ibid: 25–31; see also editorial, Ibid:15–16) family physicians were more likely than paediatricians to become involved in helping parents to stop smoking by giving the appropriate pamphlets, suggesting that they name a “quit date”, arranging to see them again to discuss stopping smoking, referring them to a smoking cessation programme, or recommending nicotine replacement treatment. Paediatricians had less faith in parents’ wish to stop smoking and their own ability to provide antismoking advice. In the editorial a strong case is made for paediatricians getting involved.

The organisation of clinical practice in Britain is different and many or most paediatricians here would probably look upon the nitty-gritty of smoking cessation as the general practitioner’s province. Nevertheless, a paediatric consultation is, at least, an opportunity to broach the subject.

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Arch Dis Child 2001 85: 180-182
doi: 10.1136/adc.85.3.180

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