Editorial

BSPAR position statement on professionals working in paediatric rheumatology

‘It seems so obvious it hardly needs to be said: just as children differ from adults in terms of their physical, psychological, intellectual and emotional development, so they differ in their healthcare needs. They experience and see the world differently.

Children are in a constant state of growth and development which creates particular needs and demands which are of a different order from those affecting adult patients.

Their relative physical and emotional immaturity, in comparison with adults, has implications both for the treatment which they receive and the physical environment in which they are cared for’.


Earlier this year, the British Society of Paediatric and Adolescent Rheumatology (BSPAR) ratified a statement on the position of professionals working in paediatric rheumatology practice. The full document is now posted on the BSPAR website (www.bspar.org) in the public domain. The need for such a document arises from the various backgrounds of professionals currently working with children with rheumatic conditions and the importance of ensuring that there is equity of access to specialist paediatric care for this group of patients. The specialist roles of the paediatric rheumatologist, paediatric rheumatology clinical nurse specialist and the paediatric rheumatology multi-disciplinary team have become increasingly important. This is particularly so with the use of chemotherapeutic agents, the emergence of biological therapies and the need to manage effectively children and adolescents with chronic, complex diseases.

Paediatric rheumatology provision varies significantly between regions. Most of the tertiary children’s hospitals now have a service run by paediatric rheumatologists, but some have been slow to put adequate resource into these service developments. Most tertiary paediatric centres run outreach services to surrounding districts. However, the individual sites of outreach clinics have often developed in an ad hoc way by individual clinicians approaching the centres. There are still many district general hospitals where no formal links exist with the local regional paediatric rheumatology centre. Some have services run by visiting paediatric rheumatologists from adjacent districts and some have a clinic service provided by an adult rheumatologist in association with a general paediatrician. Some refer all cases to the nearest tertiary unit.

This has led to a situation where some Hospital Trusts and Primary Care Trusts still do not appreciate the specialist nature of paediatric rheumatology. This is despite the National Service Framework documents [1–4] the Department of Health Specialist Definitions set and the Royal Colleges Commissioning Tertiary and Specialist Services document [5] identifying it as a paediatric specialty. Adult rheumatologists have been called on by some Trusts to develop paediatric services. In some cases, this has been as a special interest in the field through membership of BSPAR, with focused continuing professional development and with links with the tertiary centre. However, we are also aware that many adult rheumatologists see children without these structures in place. This is not only a cause of concern for clinical governance reasons but also for the protection of individual professionals working in the field. It is not sufficient for health service providers to say that there was no better trained professional available in order to justify using an inadequately trained person to provide paediatric care. This approach has stunted the development of the speciality in some areas where an approach of making do has been adopted.

It is possible to develop a clinical network with the nearest regional referral centre in areas without a tertiary paediatric rheumatology unit nearby and BSPAR would expect that all peripheral clinics be linked in this way. It is not the preferred model of care for clinics to be run only by an adult rheumatologist and general paediatrician without reference to a paediatric rheumatology centre for advice and training. Clinical network arrangements need to apply to all members of the multi-disciplinary teams. The Clinical Nurse Specialist is a key person to support the nursing staff in peripheral clinics and community settings e.g. schools and primary care.

Authorities commissioning care for children need to be certain that professionals employed to work with children have the training approved by their professional bodies specifically for the purpose of treating children and young people with the large array of problems managed in paediatric rheumatology. The differential diagnosis relevant to musculoskeletal symptoms is so broad that adequate paediatric training is essential. The training of doctors working in paediatric rheumatology should be through a paediatric route as outlined in the RCPCH document ‘A framework of competencies for higher specialist training in rheumatology’ [6].

The Department of Health Musculoskeletal Framework Document 2006: ‘A joint responsibility: doing it differently,’ [7] states that ‘musculoskeletal conditions are the biggest cause of disability in children, accounting for failure to reach educational, social and physical milestones for many of those affected. It is essential that multidisciplinary teams develop expertise to assess the needs of children with musculoskeletal problems as well as those of adults’.

For this reason, the BSPAR position statement emphasizes the broad nature of conditions that are treated and especially the many statutes and requirements with which those treating children have to comply. These include important child protection issues. ‘Child protection training is essential for all health professionals engaged in services for children. It is not an optional extra.’ This is taken from ‘Safeguarding children and young people: roles and competencies for health care staff,’ April 2006 Intercollegiate Document RCPCH, RCGP, RCN, CPHVA, Amicus and has been supported by the Department of Health [8, 9]. Adult practitioners are often unaware of and therefore vulnerable about the fact that all staff associated with paediatric patients, including clerical staff in the clinic, should be subject to Criminal Record Bureau checks, and to at least the Basic Awareness level of training in Child Protection. Staff members who work directly with children require at least level 2 child protection training. This is a statutory requirement in the Children Act 2004 and in paediatric practice the definition of childhood extends until the age of 17.

Principles covered in the BSPAR document include Training and Competencies, Codes of Professional Conduct, Continuous Professional Development, Commissioning of Specialist Care, Managed Clinical Networks, Standards of Care, Complex Patients And Specialist Services, Age Appropriate Services and Environment, Links with Other Agencies and the Multidisciplinary Team.
A list of 40 essential key documents that apply when delivering care to children is included and it is incumbent on providers of care to children to know about and to comply with these.

Adult rheumatologists have made an important contribution over the years to the care of children with musculoskeletal disorders, often through their own dedicated care. Many continue to do so and many members of BSPAR are adult rheumatologists and Allied Health Professionals working with both adults and children. This broad membership is one of the strengths of the organization of BSPAR. As appropriate adolescent care and then good transition planning to adult medical care is part of the role of professionals involved in the care of paediatric patients it is an area where collaboration between paediatric and adult rheumatologists should be developed more fully in the future.

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References