THE QUALITY REVIEW SERIES

Child Friendly Primary Health Care

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Action for Sick Children

Action for Sick Children (National Association for the Welfare of Children in Hospital Limited).

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My rights as a child are:

To have someone I love with me whenever possible,

To be told what is happening to me,

To ask questions and be given answers I understand,

To not be alone if I am sad,

To be able to play, even if I have to stay in bed,

And;

That people are honest with me,

That the people who care for me understand children's needs,

That I am safe,

That my body is my body,

That I am respected as a real person with feelings and rights of my own,

That my well-being is the most important thing

And I am part of a family.[14]

1. Introduction

The general practice is the first and most frequent contact that children and young people have with the health service. The primary care team can provide an integrated and comprehensive service for children and their families and act as an advocate for children and their families. As many health professionals know providing services for children and young people takes different clinical skills and knowledge than providing services to adults. It is important to develop child-friendly practices for several reasons:

- Young children are physically, psychologically and physiologically different from adults. The condition of a baby or a young child can suddenly get worse with potentially serious consequences. Professionals without relevant experience or training may miss important signs in sick children.
- Children are also emotionally vulnerable and may become distressed when they are examined or treated. Bad experiences of health care can have damaging and long term effects and signs of emotional distress may not be recognised.
- Children are part of a family so primary care staff need to listen to parents and carers, share information with them and support them in the care of their children.
- Children's needs change as they get older and so services must adapt to these. Older children and young people may want privacy and not want to use the same service as their parents because they fear that what they say will get back to them.

This booklet provides ideas for the primary health care team, based on the experiences of children, young people and their parents. It suggests how practices can review their own services and assess the quality of specialist health services to which they refer children and young people.

2. The primary health care team

There are several ways that primary health care teams can make their services child and family friendly and encourage young people to use them.

Developing services for children and young people requires a commitment from all the team and may require additional resources. The health authority may be able to help practices identify resources to improve facilities and provide training for staff.

Partnership with parents

Parents need to be involved fully as partners with professionals in the care provided for their child. They hold a child health record and this should be kept up-to-date so that all professionals concerned with the family know what care has been provided. For children with chronic conditions, information about a child's medication and other relevant matters should be included. An out-of-hours doctor may be unable to treat the child without this information. All staff should be encouraged to copy any letters they write about a child to parents and to write in a way that they can understand.

Sometimes parents are anxious about their child and need reassurance. They find it helpful to have arrangements where they can speak to a doctor or health professional by phone, perhaps at a fixed time each day and with the help of an interpreter if necessary. This service needs to be publicised in relevant languages, where appropriate.

The surgery is often where parents first seek advice and information. Some surgeries have information about local services, voluntary organisations, self help groups and health promotion in the waiting area. Videos on health issues can be provided on loan to patients. If they are available in other languages, they may be used by women who have difficulty leaving the house unless accompanied by a male relative. The local health promotion unit may have videos in community languages available on loan.

Interpreting services are available for non-English speaking patients through health authorities, local authorities, voluntary organisations and commercial organisations. Teams should consider making arrangements to use them, when appropriate. It is important that patients know about them and can request them.

A child friendly environment

A child friendly environment can help to reduce the anxiety of children and their parents when they come to the surgery. Wherever possible there should be an area for children to wait, with toys and books for different ages, as children who are bored distress their parents and disturb other patients. During consultations or treatment, distraction can be provided with toys, posters, mobiles or music boxes.

The environment needs to be safe for children. They should be protected from any hazards such as electric sockets, needles and medication. Medical equipment should be out of their reach and out of sight, as far as possible, as it can be frightening.

Primary health care staff

All staff, including those in reception, need skills in communicating with children and parents. In some larger practices, one partner may wish to take a lead in paediatrics, keeping up-to-date on research and good practice and passing this on to colleagues. A member of the primary

health care team can also take a lead in adolescent health and issues affecting young people, such as substance misuse, sexual health and eating disorders.

Links with other professionals working with children are important including health visitors, community children's nurses and school nurses. Nursery nurses can be employed part-time as part of the practice team to help create a child friendly environment and help during child and baby clinics.

Child health promotion

The primary health care team is involved in three areas of child health: immunisation, child health surveillance and health promotion. [1]

Most disabilities or developmental problems are identified by parents, not by professionals during screening programmes, and so it is extremely important to listen to and take account of what parents say. GPs who undertake child health surveillance should have appropriate training and work within health authority or board guidelines.

Primary care staff, especially health visitors, have an important role in giving parents information and advice on the care, behaviour and development of children. They are in touch with families and can give extra assistance to those most in need. Parents are sometimes worried because they receive conflicting advice from professionals about breast feeding, infant feeding, sleeping, toilet training, immunisation and discipline. There should be a coordinated policy between hospital maternity services, community services and primary care staff to ensure parents receive consistent advice.

Minor surgery

It is well known that surgery and anaesthesia for children require specific skills and knowledge. Therefore, GPs should not undertake any surgery on children under five, unless there is a clear immediate need and the GP has the training and skills to do this. Minor surgery should only be undertaken after the child has been told in detail what to expect during the procedure and consent has been obtained from the parent, and child if appropriate. (See page 6)

Children with special needs

Children with special needs may receive care from the primary care team, local authority services, voluntary organisations and local child health specialist services based in the community and in hospitals. Liaison is essential between all the services involved. Practices have an important role, not only in early recognition and appropriate referral, but also in providing continuing support to children with special needs and their families.

Families do not always understand how the NHS works and so need clear information, especially on referral to specialist services, to avoid misunderstandings and to prepare themselves for contact with unfamiliar professionals.[2] In addition, they need to be kept informed about their child's progress and specific needs.

Children with chronic conditions and disabilities

When parents find out that their child has an impairment or a chronic or life threatening illness, they may feel many confused emotions - anxiety, fear, guilt and self doubt. The attitude and support of the primary care team can make all the difference to how parents cope in the future.

How far care and support is provided by the primary care

team or by specialist child health services will depend on the condition, expertise in the practice and the views of parents. GPs can share the management of a child with the children's service, using guidelines for specific conditions that define the clinical responsibility of the primary care team and specialist staff. Parents need to be fully involved in making these arrangements. Multi-disciplinary care plans can be used by professionals in hospital and the community to record the care they have given and note any changes, omissions or additions to the child's care. These care plans can be held by parents.

It is essential that services are coordinated. A named member of the primary care team should be appointed for each child and family to be responsible for coordinating services and liaison with the child's key worker. They should ensure that families know about, and are able to obtain, services provided by voluntary organisations and the local authority, such as aids, equipment, wheelchairs, housing adaptations and support groups.

Children with mental health problems

It is estimated that between 10 and 20 per cent of children will at some time have a mental health problem for which they need help. GPs, school nurses and health visitors are often the first contact for families and can provide a service that does not stigmatise or 'label' them. It is important for families to be able to ask for advice at an early stage and so all primary care staff in contact with children need to have access to sources of help for parents concerned with the difficult behaviour of their child.

Specialist services for children with mental health problems are inadequate in many areas, with long delays for appointments. Professionals working with children, who have appropriate training, can help to identify problems early and offer advice and support to them and their families. The NHS Health Advisory Service recommends the appointment of primary child and adolescent mental health workers to support and educate professionals in direct contact with children to recognise mental health problems and refer when appropriate to more specialist services.[3]

Older children and young people

Adolescence is a tough time. Young people are concerned about their relationships, sexually transmitted diseases, contraception, nutrition, acne, weight problems and exercise. Staff can explain the risks that may be involved in unsafe sex or substance misuse during a consultation. Adolescents are more likely to see their GP than any other health professional, but research has shown that the consultation time GPs spend with adolescents tends to be shorter than that spent with patients of other ages.[4]

The primary health care team needs to look at how it can make it easier for older children and young people to ask for help. This may mean that the practice needs to start by identifying the characteristics of its adolescent population. Staff can also ask young people how the practice can be made more user friendly and have a practice leaflet written specially for them.

Young people may be reluctant to go to the practice because they think that what they say may get back to their parents. It is important that they know about their right to confidentiality and their right to register with a GP at 16 and with a separate GP or practice for contraception and how they can do this.

Clinics specifically for young people, aged from around 14-19 years, have been developed by practices which hold clinics at separate times for young people, while others join with neighbouring practices to set up or purchase a youth clinic. Alternative facilities for young people, such as the Brook Advisory Service and any other local family planning services, should be publicised in the surgery.

Out-of-hours services

Many parents become concerned about a child's condition in the evening when the child cannot sleep or is no better. Parents often do not know if a problem is serious or not, but they fear what may happen if they do not get help in time. Sometimes advice and reassurance over the phone is enough and a face to face consultation or visit is not necessary. At other times, urgent clinical assessment is needed.

These crises can be very difficult for families, especially for single parent families, even if the family has transport and a telephone – which is not always the case. For some families, it will be reasonable for them to come to the night centre for the child to be seen by a doctor: for others it may be more difficult, involving transporting not only the sick child but also other children in the family who would need to be woken up, dressed and brought along.

It would be helpful if all out-of-hours services had protocols to deal with such emergencies in children, defining when priority should be given to children, the criteria for making home visits to families and transport arrangements when parents are asked to bring a child to a night centre. For emergencies it would also be helpful if practices have in place prior arrangements for immediate referral on to acute specialist services through a link with a consultant paediatrician or access to an emergency consultation.

Such emergencies inevitably arise from time to time: it will be appropriate that contingency plans are in place to deal with each case according to their particular circumstances.

Legal considerations

Children are legally the responsibility of parents, who make decisions for them about their health care until they are mature enough to take these decisions for themselves. Professionals often have to make difficult judgements in deciding when to obtain consent from children, when to respect their confidentiality and when to inform parents.

Information and consent

Children under 16 may consent to medical treatment if the doctor believes they understand the nature of the treatment. Even very young children need to be involved in discussions about treatment and informed about what is happening in a way that they can understand. As children grow older they should be encouraged to give their views.[6]

It is sometimes necessary to make a decision about treatment with a child under 16 without consulting a parent. Normally a child seen alone should be encouraged to inform his or her parents.

Legal framework for children and young people

Confidentiality

The duty of confidentiality owed to a person under 16 is as great as that owed to any other person.[5]

Information and consent to treatment

Children over 16 have the same rights as adults to consent to treatment, even in emergencies.

Children under the age of 16 may consent to medical treatment without parental consent, provided the doctor believes they understand the nature of the treatment. However, the situation where a child under 16 refuses treatment is less clear.

Parent's rights

The parent's right to decide on a child's medical treatment 'terminates if and when the child achieves sufficient understanding and intelligence to enable him or her to understand what is proposed.' (In England and Wales this is covered in the 'Gillick' judgement by the House of Lords in 1985. In Scotland this is covered by the Age of Legal Capacity (Scotland) Act 1991, S.2 (4).)

However, the Children Act 1989 and the Children (Scotland) Act 1995 recognises that there is generally a practical need for the carer to be informed about important events in the child's life.

Child protection

If there is concern that a child may be at risk of 'significant harm', this must be reported to the local authority social service or social work department, even if this means breaching the confidentiality of parents who are patients in the practice. The well-being of the child is more important, (Children Act 1989 and Children (Scotland) Act 1995).

Should parents be involved?

When a young person under 16 seeks advice but does not want his or her parents informed, it can be difficult to assess if and when parents should be involved. Staff can consider these questions, based on the Gillick judgement.

- Does the young person (although under 16) understand the condition and the implications of the management that is recommended?
- If the young person does not receive advice or treatment, is his or her physical or mental health or both likely to suffer?
- Is it in the best interest of the young person for the adviser to give advice and/or treatment without parental consent?

Adapted from NHS Health Advisory Service, Children, young people and substance misuse, 1996.

Child protection

Health professionals must inform social services or social work departments if there are grounds for concern about the general care of a child, or neglect, or physical, sexual or emotional abuse. Local authorities have a legal duty to investigate when they are informed that a child is suffering or is likely to suffer 'significant harm'.

All staff need to be aware of the signs of possible abuse and know what to do if they suspect a child may be at risk. If they intend to disclose information to social services or social work departments, they need guidance on whether they should tell the child or parents and how they should do this. One member of staff with expertise and responsibility for child protection should be identified in each practice. Sharing information between professionals involved in the care of the family where a child may be at risk is essential. Members of the primary health care team should be encouraged to attend relevant child protection case conferences.

Checklist - How child-friendly is your service?

This checklist can be used to look at how child friendly your practice is. It is a comprehensive list which can be used to target aims and achievements, and stimulate discussion and ideas within the practice. You may be able to make some changes easily, while others may not be possible without additional funds.

1 Does the surgery have:
- Toys and books for children of different ages?
- Separate waiting areas for children?
- A secure pram and buggy park?
- Baby changing facilities?
- Breast feeding facilities?
- Wheelchair access?

2 Does the practice have written policies on seeing children:
- In the surgery?
- Out-of-hours?
- In emergencies?
- On home visits?

3 Are parents aware of how these policies operate?

4 Does the practice have a written policy on confidentiality and obtaining consent from children under 16?

5 Does the practice have:
- A policy on minor surgery on children?
- Procedures for preparing children and young people undergoing minor surgery?

6 Has the practice considered an arrangement whereby a doctor in the practice takes lead responsibility for services for children?

7 Are personal child health records issued to all parents?

8 Are the personal child health records used and kept up-to-date by all staff?

9 Do the personal health records include information about voluntary organisations for children with special needs?

10 Do parents of children with a chronic condition, or young people with chronic conditions, hold a record card that gives information about the medication and normal treatment advised in an emergency?

11 Do all children with chronic conditions or disabilities have a named person in the primary health care team responsible for co-ordinating information and services?

12 Do health visitors help to assess local needs for children and families?

13 Is there a policy for targeting health visiting to families in most need which has been developed with local authorities and voluntary groups?

14 Is there a named school nurse allocated to the practice?

15 Is there a coordinated policy between hospital maternity services, community services and primary care staff to ensure parents receive consistent advice covering:
- Breast feeding?
- Management of infant feeding, sleeping and toilet training?
- Immunisation?
- Discipline?

16 Has the practice identified the characteristics of 16 and 17 year olds on the practice list?

17 Is information on young people's rights publicised in the surgery?

18 Does the practice offer leaflets in different languages, where appropriate, that reflect the cultural needs of the community?

19 Does the practice leaflet include services available for children and young people?

20 Are parents given information in an appropriate medium covering key aspects of child care, including:

Minor accidents and illness?

When to take the child to the doctor or call the doctor?

When to take the child to the A&E department?

Feeding and nutrition?

Dealing with behaviour problems?

Help available from the local pharmacist?

21 Are health promotion materials available in the practice, including in relevant community languages, on:

- Local health services and how to get access to them?
- Local support groups?
- Specific health issues, accident prevention, immunisation?
- Preconception health of parents?
- Genetic disorders?

22 Are videos and audio cassettes on specific health issues available on loan in relevant languages?

23 Are interpreting services available to all families who do not speak English?

24 Have practice staff received training in:

How to make the practice child-friendly?

The needs of children and families with disabilities?

The needs of children and families from minority communities?

Identifying signs of children at risk?

Local child protection procedures?

25 Can parents speak on the phone to a doctor for advice:

During surgery hours?

Out-of-surgery hours?

If so, is this information readily available?

26 Is there an arrangement for obtaining the opinion of a paediatrician quickly (such as an emergency consultation clinic or phone line)?

27 Where patients are expected to come to a centre at night, are there policies about visiting sick children that take account of social factors, such as:

The needs of other children in the family?

Transport available to the parent?

Costs of transport?

28 Where the parents are asked to bring the child to the centre, are there arrangements to provide a taxi or ambulance where required?

29 Has a member of the primary health care team staff been identified to take responsibility for child protection in the practice?

30 Are services regularly reviewed to see how they can be made accessible to families who have difficulty using them, such as:

- Young people?
- Travellers?
- Families in temporary accommodation?
- Minority ethnic groups?
- Refugees?
- Lone parent families?
- Residents in economically deprived or rural areas?
- Where parents are ill or have a disability?

3. Arranging services for children and young people

The primary health care team can influence the quality of services for children and young people in hospital and community services by their referrals and where they commission services.

The primary care team needs to work closely with specialist services for children that are provided by the health service, local authorities and voluntary organisations in order to ensure that services are coordinated.

Child health services should be provided within a comprehensive service with separate facilities for children and adolescents and staff specially skilled in their care. In order for sick children to be cared for at home wherever possible, there must be good children's community services that work closely with parents.

Caring for a child also means involving parents, brothers and sisters. It has been government policy for many years that sick children should not be separated from their parents and this is particularly important in hospital.

Community children's nursing service

Community children's nursing services can provide nursing support at home for children with many complex problems, including children with chronic health problems, those who have had surgery, those who have burns or scalds or who are dying. Community children's nurses can help the GP and parents to look after a child at home so enabling earlier discharge from hospital or even preventing admission. Community children's nursing teams should be staffed by nurses who are both trained as children's nurses and community nurses. Some services operate over 24 hours.

GPs can promote the planning and provision of community children's nursing services (also called paediatric community nurses or paediatric home care nurses) though they are not yet available in all areas.[7] These may be based in acute or community trusts and each practice should have a named community children's nurse.

School health services

School nurses can work with practice nurses and community children's nurses to ensure that children with chronic conditions, such as diabetes and asthma, receive integrated care and support whilst at school. Some practices have a named school nurse who can work with primary health care colleagues to provide effective health promotion and family planning services for young people.

Local authority services

Social services or social work departments have a responsibility under the Children Act 1989 and Children (Scotland) Act 1995 to help children in need and their families, including disabled children, children of travellers and refugees. Local authorities maintain a register of children with disabilities, assess their needs for services and develop a care plan for each child.

Local authorities are required to produce a children's service plan as a basis for cooperation between themselves and health services, education and voluntary organisations. Primary health care staff should put forward their views to the health authority about what services are needed and any problems they experience in obtaining services for children in need and their families.

Outpatient services

Hospital outpatient clinics for children should be separate from adult clinics, staffed by qualified children's nurses and have a play area overseen by a qualified hospital play specialist.

Consultant outreach clinics can be more convenient for parents and less frightening for children than a visit to hospital. If clinics are held in a GP practice, this can also improve communication between hospital and primary care staff and provide experience and training for primary care staff. Where possible, outreach clinics for children should be held in a child friendly environment and in separate sessions from adults.

Consultant paediatricians should be encouraged to run daily emergency consultation clinics where GPs can send patients for a second opinion or ring a paediatrician for advice about a child.[8]

Admission to hospital

Children who are admitted as inpatients should be nursed in children's units by qualified children's nurses under the overall supervision of a paediatrician. Children should not be admitted to adult wards. Day surgery or day treatment for children should be undertaken in a children's day unit or held at different times from adult clinics.[9]

If a child stays in hospital, parents who wish, should be able to stay overnight with the child. Research shows that the involvement of parents in hospital care enables children to be discharged earlier.[10] It is important that children are admitted to hospital units that follow government guidelines which emphasise the importance of parental involvement (that is they offer free overnight accommodation and encourage parents to be present during treatment and anaesthesia). Whenever services are commissioned, such as for ENT, children should be specifically identified.

Research has shown that the outcome of surgery for children depends on the training and knowledge of both surgeon and anaesthetist in paediatric care.[11]

The Royal College of Paediatrics and Child Health recommends that hospitals which offer surgery for children should have a designated paediatric surgeon and paediatric anaesthetist responsible for the services for children. GPs should make sure that they refer children to surgeons and anaesthetists who have skills and experience with children. Children under five should not undergo surgery undertaken by doctors or anaesthetists in training without close supervision.[12]

All hospitals should have a play service and employ qualified hospital play staff. Play is important to prepare children for what is going to happen and help them to work through anxieties and fears and deal with their experiences in hospital.

Adolescents should be admitted, where possible, to an adolescent unit or a designated area of the children's ward. Adolescents need a different approach to care from that provided for children or for adults. Where there are no facilities for adolescents, they should be offered the choice of going to a children's or adult ward.[13]

Mental health services

Specialist services for children and young people with emotional or behavioural problems should be provided in the community by a multi-disciplinary team as part of child and adolescent mental health services. Children and adolescents have different needs and need separate services from each other. Timely help and support for families is important. In many areas there are delays in obtaining specialist services and this can exacerbate the problems

Checklist - Where to refer children and young people

This checklist picks out the most important points to consider when making a referral or planning for children's services.

If services do not meet these criteria, consider whether there are alternative services or how you can influence the quality of the service.

1 Are hospital and community child health services integrated so as to provide coordinated care for the child and family in the most appropriate location?

2 Are all services for children provided within a comprehensive children's service, including:

- Outpatient, day treatment and inpatient care within children's services?
- A&E on the same site as the children's unit?
- Neonatal services on the same site as maternity and children's services?
- Rehabilitation services for children?

3 Is there a community children's nursing service?

4 Are nurses in the community children's nursing team qualified both to nurse sick children and to nurse in the community?

5 Are outpatient clinics held in a special children's outpatient department?

6 Where a children's outpatient department is not possible, are children seen at separate sessions from adults?

7 Is there a paediatric emergency consultation clinic each day for GP referrals?

8 Are outpatient consultations, tests and treatments provided in clinics within reasonable travelling distance from the child's home?

9 Is day treatment carried out in a separate area from adults?

10 Are children treated in separate sessions from adults?

11 Is day treatment carried out by staff trained in the care of children?

12 Are there separate day treatment policies for children?

13 Is surgery only undertaken by surgeons and anaesthetists with paediatric experience?

14 Are all children admitted only to the children's ward?

15 Are parents able to stay with their children at all times?

16 Are there facilities for parents who want to stay overnight?

17 Are parents charged for the use of overnight facilities?

18 Is there a separate unit, or section of the children's ward, for adolescents?

19 If there is not a separate adolescent unit, are adolescents given a choice of the children's or adult ward?

20 Does the hospital have a play service?

21 Does the hospital have a preparation programme for children who are to be admitted?

22 Are arrangements for communication by hospitals with practices about their patients satisfactory:

- On diagnosis?
- On reporting progress of a child?
- To share management of some conditions?
- On discharge?

23 Is there a child development team to coordinate the care of children with neuro-developmental problems?

24 Does the child development team include sufficient and appropriately trained:

- Speech and language therapists?
- Occupational therapists?
- Physiotherapists?

25 Does the child and family mental health service have a multi-disciplinary team that includes:

- Child and adolescent psychiatrist?
- Community psychiatric nurse?
- Clinical psychologist?
- Educational psychologist?
- Child psychotherapist?
- Social worker?

26 Does the multi-disciplinary team have regular working links with:

- Primary care teams?
- Local children's services?

27 Can children with acute psychiatric, emotional and behavioural problems be seen in an agreed accepted time?

28 Are there separate mental health services for adolescents and young people?

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Information for parents

Action for Sick Children, Argyle House, 29-31 Euston Road, London NW1 2SD. Leaflets on:

When your child is sick: advice for parents about NHS and hospital care. Available in Bengali, Cantonese, Somali and Urdu. Designed to fit into a parent-held record book.

Children and pain: explains safe pharmacological methods of pain relief and gives tips on psychological methods such as distraction and relaxation. There is a page for children to assess their own pain.

Needles - helping to take the fear away. Explains ways of helping children cope with fear of injections and blood tests.

Action for Sick Children NAWCH (Scotland), 15 Smith's Place, Edinburgh EH6 8HT. Provides a parent pack.

AWCH (Wales), 31 Penyreol Drive, Sketty, Swansea SA2 9JT

Contact a Family, 170 Tottenham Court Road, London W1P 0HA.

The CaF Directory of specific conditions and rare syndromes in children with their family networks.

Information for families with special needs. Designed to fit into a parent-held record book.

NSPCC (National Society for the Prevention of Cruelty to Children), 42 Curtain Road, London EC2A 3NH.

A guide for parents: stress

Listening to children: a guide for parents

Single copies free, send stamped addressed envelope.

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The general practice is the first and most frequent contact that children and young people have with the health service. The primary care team can provide an integrated and comprehensive service and act as an advocate for children and their families.

Child Friendly Primary Health Care provides ideas for the primary health care team, based on the experiences of children, young people and their parents. It suggests how practices can review their own services and assess the quality of specialist health services to which they refer children and young people.

Action for Sick Children is the UK's leading charity dedicated to improving the standards and quality of child health services at home, in hospital and in the community. For over 37 years we have championed the cause of sick children, working in partnership with professionals at national and local levels.

We believe that children are special and very different from adults. We promote the principles of good practice defined by many government reports and guidelines, by representing children's interests in the planning of health services nationally and locally and by supporting parents in the vital role they have in caring for their sick children.

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THE QUALITY REVIEW SERIES

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CHRISTINE HOGG

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