COST and QUALITY
in
CHILD HEALTH

24th March 1987

Paper presented at the Conference held at the
King's Fund Centre in conjunction with the Joint British
Advisory Committee on Children's Nursing

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a fourm for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

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Kings' Fund Centre
126 Albert Street
London NW1 7NF
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JOINT BRITISH

ADVISORY COMMITTEE

ON

CHILDREN'S

NURSING

MEMBER ORGANISATIONS:

Royal College of Nursing; Association of British Paediatric Nurses; British Paediatric Association; British Association of Paediatric Surgeons; Royal College of Midwives; Health Visitors' Association; National Association for the Welfare of Children in Hospital; Regional Nursing Officers Group.

This Committee was formerly known as the BPA/BAPS Joint Committee on Nursing. We are a unique grouping of professional and voluntary organisations concerned with the care of children's health, and our four principal aims are:

i. To promote the health of children and their families.

ii. To raise awareness of the nursing needs of children and their families.

iii. To work towards the improvement of children's nursing care both in hospital and the community.

iv. To provide a forum for discussion.

This is our first conference and we are grateful to the King's Fund Centre for their support and hospitality.

CHAIR: JEAN LOVELL-DAVIS
SECRETARY: SUE BURR
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COST AND QUALITY IN CHILD HEALTH SERVICES

The Joint British Advisory Committee on Children's Nursing was set up in 1985 as a successor to the British Paediatric Association/British Association of Paediatric Surgeons Joint Standing Committee on Children's Nursing. Our members are representatives of organisations concerned with the health care of children. Our first conference took place on March 24th 1987 at the King's Fund Centre and we are grateful to the Centre for their support and help in organising it.

In the 1981 document "Care in Action" the government identified services for children as a priority and stated its concern that health authorities should develop plans for an integrated child health service. However, since the Griffiths reorganisation of the NHS, the management of children's services has been increasingly fragmented and priority has more usually been given to other client groups. This lack of focus on the health care needs of children has concerned us as a committee.

We believe it is important to identify these particular needs, develop policies, train staff and provide services for this client group and their families. The acute shortage of sick children's nurses is part of this lack of focus.

To our first conference therefore we invited health authority members, managers and planners who have Regional and District responsibilities to provide for the health care needs of children. The conference was sold out immediately; those who could not attend asked for papers.

A successful conference like this one depends on speakers who speak, and who enthuse the audience with their own concerns. We did not ask speakers for formal papers but, so that readers may share some of the experience of those who participated, we print here a record of what was said.

Readers who wish to comment are invited to contact the JBACCN, c/o Royal College of Nursing, 20 Cavendish Square, London W1M 0AB.

Jean Lovell-Davis
Chair

PP4736p

DEPARTMENT OF HEALTH AND SOCIAL SECURITY
Alexander Fleming House, Elephant & Castle, London SE1 6BY
Telephone 01-407 5522
From the Parliamentary Under Secretary of State for Health

Lady Lovell-Davis
NAWCH Director
Argyle House
29-31 Euston Road
LONDON
NW1 2SD

24 [illegible] 87

Dear Lady Lovell-Davis

I welcome the initiative by the Joint British Advisory Committee on Childrens Nursing, through this conference and their future programme, to bring together those concerned in providing nursing care to children. It will help to underline the view we have always taken that children should be cared for by those who understand their special needs.

Initiatives to improve co-operation between all those involved must be a contributory factor towards improving the quality of care provided. We must never overlook the potential confusion for parents and children when faced by the many different skills which the health service has to offer.

I wish you well in your first venture.

Yours sincerely

EDWINA CURRIE

COST AND QUALITY IN CHILD HEALTH

Tuesday 24 March 1987

CHAIRMAN: Arthur C Taylor, Chairman, National Association of Health Authorities and Chairman, Newcastle Health Authority.

Page

SPEAKERS:

CHILDREN'S SERVICES - THE PROBLEMS AND PROSPECTS OF RATIONALISATION

by Roy Meadow

Sometimes by looking at the past we can understand our present position better and see the future more clearly. 100 years ago most children's hospitals were being created by wealthy Victorian philanthropists and industrialists. By the end of Victorian times just about every city in Britain had a children's hospital as did most of the large towns. They had a difficult time in the inter-war years because of finances but when they were rescued by the National Health Service in the late 1940s they blossomed into tremendous services for children so that by the 1950s a children's hospital provided what is best in children's care - a comprehensive service.

Children's Hospitals

When you look back on what those children's hospitals of the fifties were providing, that is really what we should be providing now. They had in one place not just general medical and surgical admissions for children, but also children undergoing orthopaedic procedures, ENT operations and eye operations. They had short-stay patients, they had long-stay patients. Although they might have had a separate ward for infectious diseases, by and large it was a patient-orientated service; so they had a ward for infants, a ward for toddlers, a ward for school children complete with school teachers and school facilities, and a ward for older children and adolescents. Many of them had a ward for disturbed children and the mentally ill, run by the child psychiatrists. The outpatient department was comprehensive too. Children with ENT problems were seen there; the eye surgeons came and did clinics there; and the dermatologists came and did their clinics.

The casualty department was staffed by the same resident staff who looked after the children on the wards. It provided a 24-hour service for children throughout the year, and those of us who did research into the sort of cases it handled found that 70% of children presented with 'medical' problems, rather than just trauma because the poorer of those towns and cities came along and used the casualty department as a very important primary care service. Those who could not get on with their doctors or those who had poor doctors relied on the children's hospital to provide an effective service. Because things were grouped together, the children's hospital could create facilities that were close to where children and families lived. Creches for brothers and sisters to stay when parents visited and family units for families to stay when the child was in hospital were created. Dispensaries, X-ray, physiotherapy and occupational therapy departments were all skilled with children, because children were their only customers. The aggregation of children enabled staff to become experienced and skilled, and they often had something that many of us forget: the marvellous links with the local community.

The health visitors would pop in for a cup of coffee with the casualty sister to discuss a particular family; the local GP would visit at the end of the morning because he knew the consultant would be around in the outpatient department to discuss a child. The Lady Almoner had close links with the social workers who used to come into her office from the locality. The school attendance officer would call into the outpatient clinic. The children's hospital was a resource centre. Very often it had its own infant welfare clinic on the premises too. It was a geographical place as well as a place of spirit and of skilled staff and it was administered by a hospital committee who never needed reminding that their priority was children. It was automatically accepted in those committees that children came first and the service was for children and families. They did not need university lecturers to tell them about the value of children's medicine, that it was the most effective preventive medicine that was possible because children were the future of the country; they didn't need lectures on the "Quality of adjusted life year index". They knew it was common sense to give priority to children's health.

Children in a District General Hospital

Much of this was lost in the 1960s and 70s by the move into district general hospitals and the arguments for each DGH being as self-sufficient as possible. Closing down small uneconomic hospitals, using beds more effectively, ensuring that all patients, whether old or young, have access to modern diagnostic imaging and laboratory facilities seemed worthwhile. But the argument that particularly swayed those concerned with children about the need for children to move into district general hospitals was in relation to two aspects: (1) Accident and emergency services, because children are and always will be tremendous attenders in A&E departments (perhaps a quarter of all attendances) and the absence of paediatric expertise on a DGH site would be adverse for those children. (2) Paediatrics and children's services in general need to work closely with the obstetric and neonatal services.

I was an obstetric senior house officer at Guy's Hospital in the 1960s when newborn babies were still being looked after by the obstetric staff. I remember as the resident obstetrician, when looking after a small baby fitting or very jaundiced, having to ask the consultant obstetrician for permission to involve a paediatrician That permission having been given, I had to write a request slip to the consultant paediatrician, put it in an envelope and leave it in the front lodge of the hospital for the paediatrician to collect next time he came into the hospital. That was neonatal care in the 1960s. It had to be a very tough small baby to survive my care. When I look now at what a good neonatal unit achieves, I am lost in wonder. That a baby of 30 weeks gestation has a 100% chance of survival at birth is incredible, as is the fact that a 28 week tiny preterm baby has a greater than 9 out of 10 chance of living. The advances in this obstetric paediatric interface are little short of miraculous and many of them have resulted from having paediatricians on the site of the district general hospital. Neonatal care is very staff-intensive. You cannot support a good neonatal service unless staff are on the premises and senior staff are able to be involved.

Other results of moving children from small children's hospitals into large district general hospitals are less satisfactory. The average DGH will have two children's wards in a modern block. It is usually a block in which the wards originally were not constructed for children; they are modified adult wards because there had been so many changes in the planning process - originally designated for genito-urinary adult beds they ended up with children after minor modifications. The children's outpatients will be in a nice modern outpatient block but since the paediatricians themselves only use these suites for three or four sessions a week, they are essentially adult medical outpatients and they can't be modified completely for the benefit of children because children are not the main users. There are children being seen in eye outpatients, orthopaedic outpatients, ENT outpatients, but very few of those clinics, in England at any rate, have special clinics for children, nor facilities for children, so of course those clinics don't have rooms where mothers can change or feed babies. In the average district general hospital there will be a child development centre for the assessment of handicapped children, and it is usually in a Portacabin beside the car park. The child psychiatry unit will usually be in a Victorian house a couple of miles down the road which used to be a child guidance clinic or alternatively in the basement of the now disused infirmary on the other side of the town in the old premises of the VD clinic. The A&E department will be a modern A&E department in the district general hospital but though about 20,000 children a year will be attending it, they will be mixed up with the adults and there will be no special facilities for children. That is usual. Some places achieve rather better services, some a lot worse, but my description is what we all know is usual. The conclusion is that when children's hospitals moved into the DGH, children's services were at best disintegrated or at worst abolished. Therefore I am fearful whenever I hear of children's hospitals being destroyed. I am less fearful than I used to be because I think most authorities now try and make sure that if a hospital shuts, the resources go back into that user group. In the past children's hospitals were destroyed and money was put into a big kitty and never went for the benefit of children.

Sadly DGH services have become separate from the community. Those working outside hospital, whether they are health visitors, school nurses or special school staff have difficulty finding paediatric staff in the big district general hospital and there is no one place in it to which they can go as a resource centre or contact centre; separation has increased.

So what should those few cities and towns that still have a children's hospital do now? Regional centres such as Birmingham or Manchester are in a very difficult position, because they are providing tertiary referrals for some very complicated problems and often these are complicated organ specialties, involving procedures such as liver transplant, dialysis and heart surgery, and those logically have to be allied to the adult service to justify the resources.

Tertiary Referrals

I will digress for a moment to remind those who are not aware of the unusual position that children's tertiary referrals occupy. A tertiary referral means a referral from outside one's own district by another consultant, in other words a paediatrician in a DGH referring a child to a paediatrician in the regional centre because a child has a major problem. Tertiary referrals for children are proportionately much greater than they are for adults. If an adult has an awkward neurological problem in a district general hospital the physician consults the neurologist who is either on the staff or visiting that hospital. The patient doesn't move to another hospital unless he needs a brain operation. If a paediatrician is faced with a very difficult neuro-developmental problem, he does not consult the adult neurologist who visits or attends or is on the staff for that hospital. The paediatrician refers the child to the paediatric neurologist in the regional centre, and that applies for malignant disease and severe diseases of the liver, kidneys, etc. This means that for those places which are tertiary referral centres, an extraordinarily high proportion of their patients come from outside their own district. Most of this work is not funded by the referring district or region, and this can cause enormous problems for the ordinary children of that teaching district.

For the large British children's hospitals in regional centres, receiving many tertiary referrals and dealing with complicated organ sub-specialties, there are advantages in being on the same site as the regional centre for adults requiring dialysis, transplantation or other complex technology. But if they do move to the main teaching hospital site they must ensure that they don't lose the comprehensive nature of their children's services and all the great qualities that they have at the moment. The ideal would be to lift up their present hospital and put it in a separate building on the main site.

What should a non-teaching children's hospital do? I think if I were in Brighton, I'd hang on to my children's hospital, because I don't think they have much to gain by moving to a district general hospital site. They don't need the expertise of a DGH and they stand to lose a great deal by shutting the children's hospital. They should only do so if they are absolutely sure that the many good things about their small children's hospital can be replicated on the main site.

The Way Forward

Most of us have already been district general hospitalised. What can we do? One way forward is to regroup as many of the children's services together as possible. Outpatient care is very important and so is day patient care. Ideally inpatient and outpatient care need to be adjacent. All outpatient services need to be together with the child development centre and with child psychiatry because in that way one can begin to justify pram shelters, the crêche services,the staff and everything that children need. We must recreate the links with the community. There have been many interprofessional problems between hospital doctors and community doctors. It is tragic that when the professional problems are being overcome the geographical and organisational problems are greater than ever. Today the children's services will be in the general hospital unit or the acute sector unit, while the school nurses, the health visitors and the clinical medical officers will be in a separate management structure for the community. The average general hospital really should have its children's services, both hospital and community, in the same unit. That is not appropriate for teaching hospitals because of the different structure of their work.

All NHS staff have had to contend with successive and disruptive reorganisations and with changes of medical practice. Children's nurses have had to adjust to massive change. In the 1940s and 1950s the wards were their territory: children were neatly in bed and visitors were few and controlled. By the 1960s parents were often on the ward though the children were still in bed. Today in a modern ward there is difficulty working out who is the patient, who is the parent, who is the visitor and who is the nurse. (What I usually do on my rounds, since most of the patients are on intravenous drips, is to follow the plastic tube along to a person and assume that is the patient.)

Many mothers stay in hospital with their children. Wards may have three or four rooms to accommodate parents on the ward. Yet constantly there will be up to 18 parents resident at a time. The other 12 or 13 who are not in parents' rooms will be on the ward floor, on mattresses, on their child's bed, or on camp beds.
It is very difficult for the nurses. Most nurses will be learners or untrained with children and to have to deal with his combination of mothers with children is a daunting task. If they are on the neonatal unit and the baby is old enough to be handled then it will be the mother who is doing the handling rather than the nurse. In many ways nursing is less satisfying. The other factor that has made things difficult for nurses is the length of stay of children. Great efforts have been made to keep children out of hospital and to reduce length of stay. The usual length of stay is no more than two or three days which can be very unsatisfactory for nurses. They don't have the joys that I do of outpatient follow-up and sometimes seeing people in their homes.

Children Lack Representation

How can we achieve change? There is a prime need to identify someone or some organisations which speak for children. Children in Britain have a low priority compared with many other countries. A few organisations do speak up for children: the NSPCC always, the British Paediatric Association and the National Association for the Welfare of Children in Hospital sometimes, but the power barons in medicine are the British Medical Association, the Royal College of Physicians and the Royal College of Surgeons. They can never be expected to speak up for children because they have to be mindful of their majority interest which is adults. What happens nationally is reflected locally. While there may be a paediatric division or paediatric committee in many districts, paediatric representation on the medical staff committee or medical executive committee will be small - no more than one person. You cannot expect these district representative committees to speak up for children. Anaesthetists, pathologists, physicians are not hostile to children, merely mindful of the majority interest, and of their main customers who are adults. Children have very little impact on services for adults. Certain other groups, for example old folk and the mentally ill, have a major impact on the life of physicians and surgeons: they sometimes block their beds, and that matters. Other minority groups are important in the wheeler dealer area of private practice reciprocal arrangements, but generally children are outside that.

Since senior medical staff and organisations are unlikely to speak up for children we need others to be more forceful. That has always been so in our society. In the nineteenth century there were great pioneers who cared about children and the conditions of their work, health and education. Some were politicians, all were people of vision, and they were individuals who spoke up for chidren. We need political leadership today. We need leadership from district health authorities who are meant to be representing the customer. They must represent people who cannot speak up for themselves and especially children and the handicapped.

As a member of a health authority I know that health authority members are conscientious and caring people, but I also see the problems they have with professional matters because they are lay people and when the topic becomes clinical or professional they are anxious to take account of what the professionals say. "Let's ask the district medical committee." It is inevitable that they will do that and of course they get the majority interest. There is a need for people on district health authorities to remember their responsibilities to minorities.

What about the administrators? I have immense sympathy for administrators on their short term contracts with a bonus on pay if they achieve certain financial savings. They are in a difficult position, and the planners in an even worse. They have central directives to sell off land and close outlying hospitals. It is not surprising, therefore, that district strategic plans tend to resemble a get-rich-quick asset stripping operation by ambitious entrepreneurs rather than a carefully considered health plan for the needs of the community by people who are committed to that community and care about it.

Children - an Urgent Priority

The need to improve services is urgent. Most of us are rather too familiar with graphs showing the decline in mortality for children. If you analyse mortality for all children over the age of one those curves have mainly flattened out. Mortality rates no longer go down and are more or less level for many disorders. And the signs are that morbidity, childhood illness, is increasing. There are several reasons for this.

Medical advances, whether they be in neonatal surgery or cardiac surgery, leave a certain morbidity behind which is very costly to families and the health service. Moreover if you ask how many children have been to their general practitioner in the past two weeks, the answer is 20% of children under 5 and 10% of children over five. That is an increase of 100% in the past ten years. In many areas childhood morbidity is increasing. When you set that beside the facts that 40% of children do not get immunised against measles, that 82,000 children were in care (before the explosion in the detection of child sex abuse) and that this year 4,000 14 year old girls will become pregnant, one's worries increase. The worries escalate as the statistics and research reports emerge - the continued rise in smoking cigarettes by school children, the continued rise in one-parent families (an increase of 100,000 one parent families in the past five years), and the increase in poverty. One third of families are below the official poverty level and those are the families with children: the 'poverty trap' is to do with children. A married family with four children can double their pay from £60 to £135 and still no extra money comes into the family because of the increase in tax and withdrawal of means-tested benefits. It is children who are in the poverty trap. When we think of these families, we have to say that children are in a mess and that the matter is urgent.

Most of us subscribe to the concepts of the Child Health Services Committee report, the "Court" report. We should still be aiming for child and family centred services with skilled help available and accessible for every child. We must promote the integration of preventive and curative services and the link with educational medicine. We must achieve these objectives fast. It is up to all of us in our various capacities to clarify and emphasise the needs of children, so that Britain will create better services for children.

TOWARDS A BETTER MANAGEMENT OF SERVICES

by Stuart Dickens

To make my point I need to start somewhat provocatively. Here are two opening statements:

1. Child health services are arguably the least well managed of our health services.
2. The answer to the question, "We don't spend enough on child health, do we?" has to be - in all honesty - "I'm not sure..."

How many authorities having determined their strategic goals - as they will have for their child health services - can readily convert their statements of intent into coherent operational plans which have the commitment of all those staff working for children in each district?

There is rarely any single focus for the delivery of the child health service: paediatric beds usually fall within the ambit of the Acute Unit; the school health service is more often than not directed by an SCM based in the DMO's department with school nurses managed in the Community Unit; health visitors, whose role is so crucial in child health surveillance, are managed within another framework. And, to reinforce my point about resources, how can we objectively answer the question about the amount we spend or ought to spend on child health if the average authority has no idea what total resource is spent on the service? Budgets for the child health service are like shards of pottery on an archeological site: it takes some time to get any notion of what the whole pot might have looked like.

In reality, and as a sweeping generalisation, we are not managing services and service delivery; we are managing institutions and infrastructure. We can only begin to address questions of effectiveness, value for money and the relative priority of differential investment when management is concerned predominantly with service delivery and a genuine reconciliation of service objectives with the total resources available. I have seen this as the challenge for the General Manager, but in effect it is a challenge for the whole service.

I have to say that any serious consideration of the issues involved here has to start from the basic question: what kind of business are we in? This may seem a rather obvious question but if it is so obvious why do we spend most of our energy on managing institutions rather than services? Surely the health authority's business is health care, and in essence the enhancement of the health status of the population we serve. This is the mission statement for South Birmingham Health Authority:

> "The Authority's main responsibility is to enhance the health status of the people of South Birmingham and management should be geared to the achievement of clearly defined objectives for the improvement of health care and the delivery of services."

It figures therefore that the management issues are not structural, ie what management structure should South Birmingham Health Authority have? - but, how do we organise health care in South Birmingham? Structural considerations ought to follow the answer to that question. I am fundamentally unhappy about units of management that reinforce the notion of managing St Elsewhere DGH and equally the view that community services (a rather abstract title) should be hived off and given 'protected' status.

In South Birmingham we used to have eight units, seven of them based on institutions and one identified as the 'community unit.' We now have three, and three that are based on a federation of care programmes rather than institutions.

The answer to the question, "How do we organise health care?" is within health care programmes devoted to the major client groups, one of which is children. Unit structure has emerged out of the management arrangements for service delivery rather than any preconceived notion about geography or institutional infrastructure.

So what is programme management? Programme management is concerned with providing service direction and cohesion to all those resources devoted to a client group in order that the needs of the client group are most effectively met with the resources available.

Now each programme has a Programme Director, and the Director for Child Health is a member of the Family Services Unit Management Board and is accountable to the Unit General Manager. The Programme Director's role is crucial and worth spending a little time on. The key responsibilities are defined as:

Providing programme leadership.
Accounting for performance.
Establishing and monitoring standards.
Providing the focus for strategic and operational planning
  within the programmme.

The key elements are leadership, a focus on service delivery, and the planning and develpment of services. The structure embraces the concept of matrix management, that is the primacy of programme leadership even though individuals working within each programme will have their own functional managerial accountability, ie nurses to nurse management, physiotherapists to physiotherapy management and so forth. In essence whatever their functional allegiance staff working within the programme recognise the leadership of the Programme Director.

This slide shows the basic senior management organisation of the Family Services Unit. You will see how the Family Services Unit works - and it does work. The Unit General Manager has total responsibility for the Unit including support services and business management. His Programme Directors have an uncluttered role exclusively devoted to delivering the goods.

At this point people usually worry about those people whose needs fall outside the programme structure and indeed those staff who are known as 'generic workers' and clearly contribute to a number of client groups. The Family Services Unit is more than the sum of the programmes. For the purposes of this conference we needn't dwell on this, but suffice it to say that Health Visitors and District Nurses are managed within the Unit, providing a wide range of services across the population. It is of course these particular staff who typify the generic worker. There is no intention to box up professionals into neat programme packages, but two issues are seen to be important.

1. We need to know how much time each devotes to one programme or another.
2. Those individuals in turn need to know the contribution each should be making to programme objectives, indeed be able to contribute to the formulation of those objectives to secure genuine ownership and commitment. You will know that Julia Cumberlege's committee placed considerable emphasis on the need for objective-setting for community-based workers. The programme structure does just that.

Let me summarise the story so far. We have a single programme devoted to child health which embraces all those resources identified with the client group. We have a focus for leadership vested in a Programme Director who is a paediatrician but could have been appointed from any one of the disciplines contributing to the programme. A key factor is that the individual is a credible and able leader of the programme. It is also important to re-emphasise the point that a vehicle now exists for objective-setting and the genuine involvement of those working within the service.

What are the other essential features of the approach? Well ...

1. You need a data base, and we have put effort into the production of a Child Health Service Profile to support the programme team and programme planning.
2. It is a sine qua non of this approach that there should be a programme budget which represents all those resources devoted to the programme. This is problematical: child health resources are spread across the district and need to be teased out. However, this difficult task is under way.
3. I need also to mention that programme culture is important. Programme letterheads, newsletters, programme seminars, all promote the notion of corporateness and a sense of working for children in South Birmingham, rather than working for Selly Oak Hospital or wherever.
4. We have a market research campaign in South Birmingham which will give the programme important insight into child health behaviour.

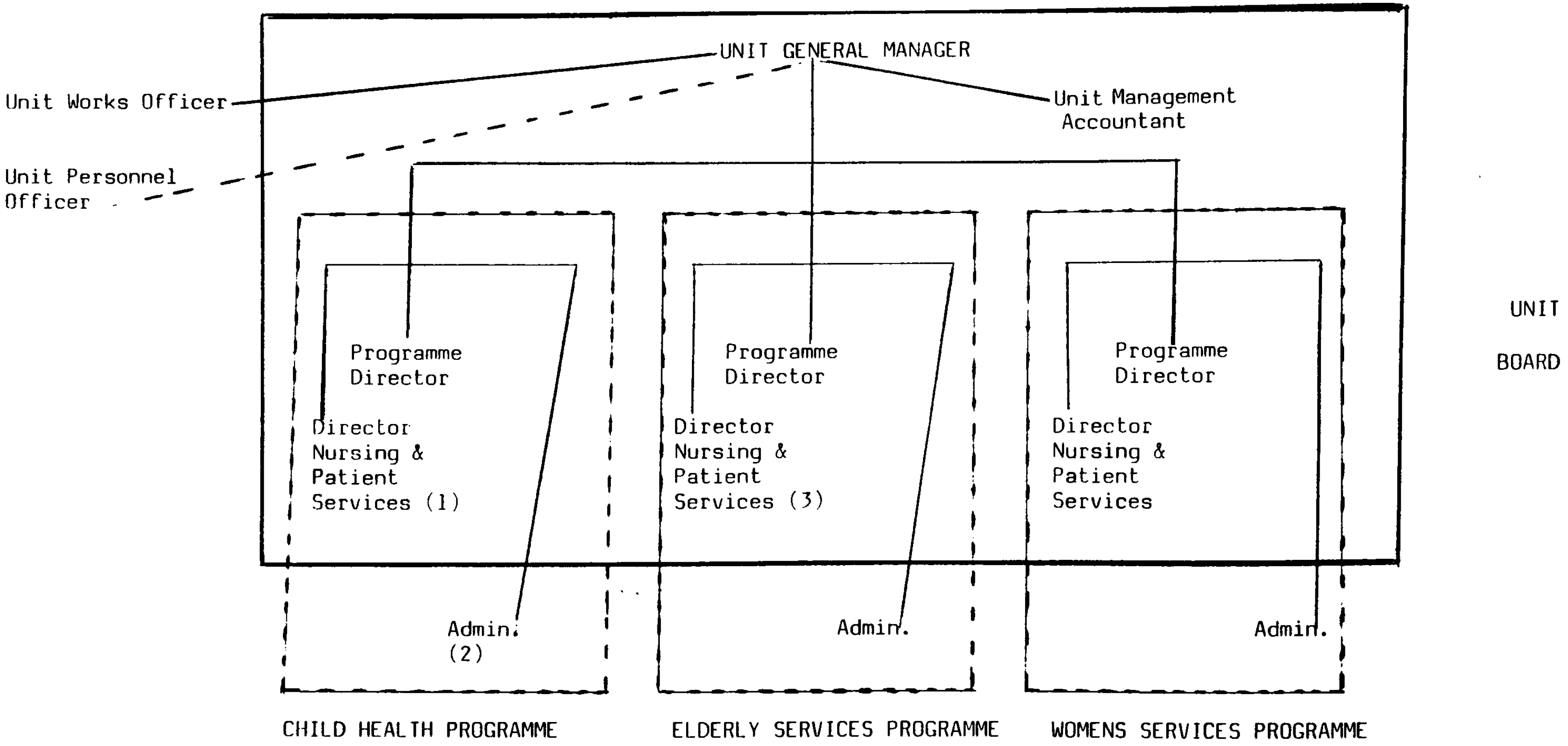
I cannot pretend that any of this has been easy. I believe passionately in the need to change the way we manage, but as an old NHS hand I know that the management of change on this scale is a long and winding road, although there are those that expected an overnight transformation. I am concerned to develop a culture which is service-delivery oriented and has no artificial boundaries to impede a genuinely comprehensive approach.

It is working. Programme objectives have already been established; there is evidence that the use of resources is being evaluated and that the pattern of service delivery is being changed as a consequence.

I am not saying that this is the only way to achieve better management of the Child Health Service, but after a year it is beginning to feel a very natural way of organising health care. In the final analysis, and as I have already said, the real test will be the extent to which individual staff feel they are working for children in South Birmingham.

THE FAMILY SERVICES UNIT

Management Structure



1. This post includes the management of Health Visitors and therefore has cross programme responsibilities.
2. This post includes Community Services administration and Health Centres management.
3. This post includes the management of District Nurses, therefore has cross programme responsibilities.

QUALITY OF CARE - IS IT MEASURABLE?

by Sue Burr

In an era when market forces and cost effectiveness are permeating health care, the ability to measure the quality has never been so vital. The title for this paper, 'Quality of Care - Is It Measurable?' suggests a certain scepticism.

What is quality? Definitions are important: how can measures of quality be assessed if the base line has not been defined? The Collins dictionary defines quality as a "distinguishing attribute," but the concept of quality is part of everyday language that we use casually. It is a value judgement which poses the questions: whose values, on what basis and whose judgement? Many of the views expressed in this paper are based on the work of Tom Keighley, formerly a colleague at the Royal College of Nursing and now District Director of Nursing, Waltham Forest Health Authority.

Quality only has meaning when related to its function, and isolation of function is rarely simple. Quality is the totality of features and characteristics of a product or service which bears on its ability to satisfy a given need. That need is measured against expectation. Standards are used to measure features against which judgements are made. The World Health Organisation (WHO) definition of standards of care is "an agreed level of care required for a particular purpose." Quality is relative: the quality of a King's Fund lunch appreciated by adults is, for example, not a quality measure relative to a three year old child. The quality of competent technical skill required to nurse a baby receiving continuous positive airway pressure (CPAP) - a form of respiratory support - is very different from those expressive/affective skills required to support the baby's family.

In reviewing quality, it is important to realise that expectations change. In 1987 society expects children to reach adulthood, in direct contrast to the early 19th century when children's hospitals were established. The National Association for the Welfare of Children in Hospital (NAWCH) Charter for Children (1984) portrays the expectations of parents and those who care about the hospital experience of children. An important measure of quality, therefore, is outcome.

What is 'Quality Assurance'? Where did it come from? Why is it an issue in the UK in 1987? Quality assurance is a process to enable a predetermined outcome to occur. It was founded in the munitions industry. An unskilled workforce was required to produce, at speed, munitions which when fired had a predetermined outcome. Inspection and supervision to ensure standards imposed from above was the basis of this quality assurance process. This tradition of inspection permeated not only nursing but also the National Health Service (NHS) as a whole. Such examples are Community Health Councils, the Health Advisory Service, the General Nursing Council Inspectors - now English National Board (ENB) Education Officers; and the all-important Matron's round must not be forgotten.

Quality assurance is influenced by many factors but primarily by resources. Resources, or lack of them, is certainly an issue in the NHS in 1987. Quality is based on a clear understanding of the relationship between resource allocation and health outcomes. Quality assurance in nursing was evolved in the market-led USA service. Insurance companies demand value for money but the passage of 'medicare' and 'medicaid' legislation resulted in the enormous financial responsibility for providing health care for the elderly and poor.

This prompted policy makers to believe that planning related to money, and quality assurance controls were needed. In the UK the NHS provided a cushion, but the writing was on the wall. Beveridge's concept in which the NHS was founded was not realistic and this led to expectations changing. Ruth Brenner, Director of Quality Assurance at the Francis Scott Key Medical Centre, USA, states, "The USA was forced to institute quality assurance programmes through fear of litigation, denial of accreditation and loss of revenue - a negative motivation, but in Britain you have the opportunity to develop quality assurance, not because you have to, but because you want to."

While I do not wholly share her belief, it cannot be said that our child health services provide value for money. A real question for managers to ask is, how much do the child health services cost? The answer is difficult if not impossible to state with accuracy because child health care is charged to so many different budget heads. The Court Report "Fit for the Future" (1976) revealed that the consumers - taken to be parents - did not understand the fragmented child health services. Unfortunately little progress has been made in achieving an integrated health service. A few examples of this fragmentation in costing terms are:

1. The normal newborn is costed to the midwifery unit, the baby often not being identified separately from the mother.
2. Those babies requiring specialised medical care for nursing purposes may be within the midwifery unit but medical care is under the auspices of paediatricians. However, is surgical care is required, the baby is moved and costed to the paediatric unit.
3. The children's ward is usually costed under acute services, but are those children placed in adult wards costed into the paediatric budget? It is also worth noting that the DHSS definition of a child is 0-16 years. The Consumers' Association Report "Children in Hospital" (1980) showed that 40 per cent of children were nursed in adult wards.

A significant proportion of Accident and Emergency attenders are children. Many A/E departments still do not identify children separately and so cannot cost care separately into the child health service budget.

Who nurses children in the community? Is that identified? If so, under what budget head? Atwell & Gow's work reported in the BMJ in 1985 showed that paediatric community services were an economic necessity, not an expensive luxury. It is therefore not surprising that similar schemes are rapidly being developed throughout the UK. Prevention and child health surveillance are integral to early identification of problems which may affect the child's future health outcome. How much does it cost and how cost effective is it?

Lack of resources is a fact - the Gross National Product is not a bottomless pit. Increasing expectations make real demands which immediately raise ethical issues. For example, should every baby, however small, however handicapped, automatically receive all the intensive care skills yet devised? The competing demands of other client groups such as the elderly, the mentally ill and the mentally handicapped mean prioritisation and rationalisation have to occur. Are the resources available being put to the best possible use for appropriate patient outcomes? Could it honestly be stated that X number of pounds extra would directly improve the quality by a measurable criteria? This is the quality argument. But quality is free. Elimination of error equals cost reduction. Enhancement equals cost.

Professional Development

Accountability also affects quality of care. Florence Nightingale in 1859 in "Notes on Nursing - What is it and What it is not" included standards both of the affective and technical nature - a quality of care was to be striven for. As the education of nurses developed in the USA, so did work in the field of quality. Virginia Henderson pushed open the realm of individualised and holistic care. Measuring quality has always been integral to the development of nursing as has public accountability. In less than a hundred years, nurses have developed from a subservient handmaiden position to an independent profession accountable for practice within the full rigour of the law. The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) was required by law to produce a Code of Professional Conduct. All aspects of the Code have a relevance to standards but particularly the following:

> "In fulfilment of professional responsibility and in the exercise of professional accountability, the nurse, midwife or health visitor shall...
> Clause 2 ...Be accountable for her practice and take every reasonable opportunity to sustain and improve her knowledge and professional competence.
> Clause 7 ...Have regard to the environment of care (physical, psychological and social) and to available resources, and make known to the appropriate authority if these endanger safe standards of practice.
> Clause 8 ...Accept a responsibility relevant to her professional experience for assisting her peers and subordinates to develop professional competence.
> Clause 9 ...Have due regard to the workload of and the pressures on professional colleagues and subordinates and take appropriate action if these are seen to be such as to endanger safe standards of practice."

Therefore, each nurse has a professional responsibility for the quality of their own care and a process exists by which the public can hold them accountable for it.

Consumerism

Quality is customer satisfaction. Quality is fitness for purpose, but whose purpose? Who is this service for? Who is the consumer in child health? The pressure to improve the care of children in hospital has been with parents being viewed as the consumer. The Platt Report (1959), the seminal report on the "Welfare of Children in Hospital," was the result of four mums discussing hospital care for children on a park bench. These four mums led to the formation and development of NAWCH which has achieved more for the quality of child health services in the affective aspects of care than any doctor, nurse or administrator.

The era of the child's right to be included in health care decisions is starting in the UK. The Gillick decision marked a new era in child health services. The right of the child, the real consumer, is being released from parental rights. Once more expectations have changed.

Quality is linked with providing the service the consumer wants within resources. The consumer experiences the ill health process and the health service process. What is that experience like? BUPA has three million paying customers. People are prepared to pay for an enhanced experience of getting better. Parents with the assistance of NAWCH may shop around for a paediatric unit in which they are encouraged to be partners in care. These parents know that hospitalisation is a potentially traumatic experience for children and they are prepared to seek a unit in which the philosophy of care incorporates the DHSS recommendations and the NAWCH Charter for Children in Hospital.

Consumerism has played a role in changing the system of nursing from a medical model based on disease and tasks to an individualised and holistic approach. We have proceeded from parental exclusion to parental participation and now to parents as partners in care. That progress is also seen in the community with parents in Oxford keeping their children's health visiting records. Good paediatric units are totally different from thirty years ago, not just in equipment, numbers and skills of staff, but the whole ambiance. How are requests for play materials, facilities for parents including double beds and appropriate clothes for children viewed: as expensive luxuries or sentimentality, or reasonable and appropriate requests?

Standards must be formulated which demonstrate their effect on outcome. The standards must be established by members of the profession who have received specific and appropriate education in the care of the specific client group but with regard to all other inputs. Nurses are in a strategic position to identify patient needs and to formulate the standards, but creating and maintaining standards is not enough. The cost effectiveness of raising the standard of the quality of care delivered must be demonstrated, but nurses cannot work in isolation: a multi-disciplinary approach is vital.

The society in which children live determines their physical and mental health. The value that society gives children determines the quantity and quality of child health services. Children are used emotively in all senses of the word, but acknowledgement of their rights is minimal. We have a Minister for Sport, an Ombudsman for the Health Service, but no Minister or Ombudsman for children. Why have the DHSS recommendations relating to children not been universally implemented after nearly 30 years and yet 'Griffiths' is almost old hat?

Griffiths management also has a role to play in the quality of care. The Griffiths philosophy is linked to accountability for a cost effective service to the customer. It is a 'can do' philosophy. Therefore, if a manager is ignorant of a particular skill there is a tendency to shy away, to appoint the least experienced staff, and to be unable to evaluate. For example, if I were a General Manager I would not have the first idea abut evaluating the Works Department.

Total quality management is as much to do with people as it is to do with quality systems. A belief that everything done by everybody is valued and valuable to provide a quality of service is vitally important. Morale is difficult to evaluate and the vibes received from nurses is that morale is very low. The pressures they work under in attempting to produce any quality of service are immense. Thirty thousand qualified nurses leave the NHS every year. So what? But nurses form the majority of the work force and have, by far, the most contact with the customer. Nurses therefore have a vital effect on customer satisfaction, on that quality of care.

Total quality management requires support from the top. Key opinion formers need to be identified: those who simplify reality, those who help to bring about change by vision and example. Those who provide the appropriate role model. Significant work funded by the King's Fund demonstrated that the ward sister was the key factor in the provision of both quantity and quality of nursing care in her ward.

Whose Responsibility is Quality?

The NHS has many traditions which permeate care, one of which is blaming others. This occurs not only between different sections, for example managers, the professions or the ancillary staff, but also within sections. The day nursing staff blame the night nurses. The community staff blame the hospital staff. Then there is the system and structure imposed by them - whoever 'they' are. And the government of the day must not be forgotten.

The NHS requires total commitment by all of us: one section cannot succeed without the other. The Japanese have a good record of quality assurance. A much-quoted Japanese saying states "Education is the key: first make the person and then the product." If nurses are expected to be involved in giving high quality care, then we need to invest in their education in the way suggested by Project 2000. Today, cost and quality in child health is being considered. How does education apply to those here today? How many regions have implemented the DHSS staff training memorandum 59/71? How many present today, and this is a committed audience, even know what it proposes?

Measuring - Where are we now?

Measurement is familiar to us all, commonly in numerical terms, for example, the number of under-fives on a health visitor's caseload, the number of children seen by a paediatrician in an outpatient session. But what does that measure? Standards are measures against which something is judged. Child health professionals understand this. A baby's weight is a standard against which progress can be measured. It is easily observable, quantifiable and acceptable to the consumer. But be warned: an isolated weight measurement provides only a snapshot. It records only an isolated measure and cannot alone be used to determine qualitative outcomes.

Townsend in 1974 indicated that as far as medical care provided by the NHS is concerned, statistics are available which provide an account of how many items of work are performed. This provides little data about the patient on whom the work is performed or, very importantly, about the quality or therapeutic effectiveness of the work done.

What is to be measured in a public sector service? It is the quality of the people that has to be measured. Quality of care in nursing has two major components referred to earlier, namely technical performance and expressive performance. Buswell defined technical performance as "concerned with the effectiveness with which the operational aspects of nursing are carried out, with the knowledge of nursing procedures and with the effective utilisation of technology and equipment." The technical aspect of the ventilatory support a pre-term baby may require can be measured and controlled corporatively, the knowledge aspects through training, the manpower by the number of nurses with appropriate training, the facilities available, etc. But the expressive or affective component of nursing, for example that required to support the baby's parents, is not so easily measured. Buswell defined expressive performance as "being concerned with the attitudes of staff, with their relationships and interactions with customers and with the manner in which staff deliver the nursing service. It is essentially people-based." How can this, which is dependent on the inter-personal skills and personality of the performers, be measured?

Statements such as "feeds a little better," "seems more alert," and the feeling a health visitor has about a child/parent relationship, but has no objective facts, are common to those directly involved with children and their families. The question is, how can that intuition - if you like to call it that - be demonstrated, based on appropriate knowledge, skills and attitudes, and not just common sense. Nurses must do more than quantify and evaluate care of a given patient: they must be able to document the extent to which outcomes are influenced by the clinical interventions used.

Work on this aspect is in hand. Simon Old's unpublished work from Leeds showed that less than ten per cent of patients experienced a cardiac arrest without a nurse being present and yet overall the nurses were at the patient's bedside for less than ten per cent of the time. Studies are being undertaken in the Western General Hospital, Edinburgh, to show what makes the ward sister, the most experienced nurse on the ward, go to a patient's bedside. What is that intuition? How can we measure care?

It is relatively simple to devise a framework in which quantity rather than quality is the basis of the tool. Despite the vast amount of information collected within the NHS much of it fails to reveal what is really going on in relation to quality. Those involved in the hospital care of children know that the measure 'beds occupied at twelve midnight' has little relevance to the work load of a paediatric unit - particularly in units of good practice, in which early discharge is the norm, and therefore those occupying beds at the magic hour of twelve midnight are those requiring the most intensive care. The resources concomitant in the children attending the ward for treatment or advice and yet not admitted, or the communication with worried parents by phone, remain covert. This hidden care has distinct resource implications which are obviously more extensive in health authorities without a paediatric community nursing service.

The example of the inappropriateness of counting heads in beds at twelve midnight is chosen for several reasons. First, it clearly demonstrates the danger of using a snapshot, an isolated event to determine other measures. This subject is also part of a research study initiated by four organisations namely the British Paediatric Association (BPA), the Royal College of Nursing (RCN), the National Association for the Welfare of Children in Hospital (NAWCH), and the National Association of Health Authorities (NAHA), and funded by the King's Fund. It is also an example of the interdependence of all those who work to benefit child health.

Failure to collect information relating to 'ward attenders' is an act of ommission, but will the new information systems provide a measure of quality? We have Korner and MAPs and MIPs and PAs and PIs - to name but a few. My mind boggles at the amount of information to be made available. But where is the quality measurement? Performance indicators (PIs) for example, raise serious doubts in my mind. In the child health services section the number of registered nurses per hospitalised patient is to be collected. It may be assumed that that has a qualitative component, but does it? Is a nurse registered in the care of a mentally ill adult appropriate to nurse acutely physically ill children? With a slight modification, for example recording the number of nurses with the Registered Sick Children's qualification, some quality could be assumed. That children should be nursed by those holding the Registered Sick Children's Nurse qualification is a DHSS recommendation, but there is a recognised national shortage of such nurses. Are the PI's questions posed in such a way so that uncomfortable information is hidden? On a different tack, the number of children admitted with the diagnosis of enuresis is to be recorded. But what is meant by enuresis? No definition is given. What could that numerical information indicate in the realms of quality? Services in the community, varying from efficient and effective health visiting and school nursing services to designated enuresis clinics, must have a bearing on those parents who admit such a problem even exists, let alone those referred for admission to hospital.

A valid, reliable database is crucial. Remember the Gigo Theory: garbage in, garbage out. It is not simple to develop a framework in which quality can be evaluated based on norms, values and expectations. Basic values with regard to what is acceptable and what is not must be agreed. Is the best possible care the aim, or minimal levels of care to avoid litigation, or something in between? What is realistic?

Measuring Tools

What tools do nurses have to measure care? Tools such as Phaneuf's Nursing Audit, Qualpacs, the quality patient care scale and its paediatric adaptation devised by Toronto Sick Children's Hospital SAVE (Selective Attribute Variables), and Rush-Medicus and its UK version Monitor will be familiar. The Royal College of Nursing is pioneering in the UK Standards of Care, based on Donabedian's framework of Structure, Process, Outcome.

All of these tools have an inspection and checklist element. These are useful but don't really measure the expressive or affective aspect of care, the aspect the patient or client really experiences and equates with quality of care. It is important to remember that all these tools are still in the process of refinement and validity testing, and all evolved from a North American Health Care System. All the systems designed are contextually based within a culture-based event. Whilst in statistical terms there may be a low level of significant difference, what has not been taken into account is that the variables have changed. The outcome expectations are not interchangeable. The needs of a child are very different from those of an adult.

The tools to measure quality of care are still being developed. What is the significance of the information when it becomes available? We compromise. In the absence of a metre rule a yard measure is used and a bit added! However, if sound information relevant to an appropriate framework is not available, but only that which is collected haphazardly and presented as established correlations, danger abounds. We are only human and make human interpretations and mis-correlations. For example, between 1918 and 1930 the number of storks which left Britain increased and the birth rate decreased. If this was a valid correlation we would not be here today thinking about cost and quality in child health services, because we would not have a need for such services! This is really no different from correlating bed occupancy at twelve midnight to either quality or quantity of care.

There is much work to be done. Senga Bond, in giving the Winifred Raphael Memorial Lecture in 1985 said, "Measurement is essential to good nursing... The development of measurable outcomes of nursing intervention is probably the major issue facing nursing."

Quality of care, is it measurable? Well, yes it is and no it isn't, depending on the definition and within what framework. No it isn't measurable if we rely on simple snapshot event measures. In devising valid tools we must define: the customer, the outcome or satisfaction, the purpose, whether the measure is reliable, its requirement, its cost, the need it fulfils, its function, its acceptability, and its standard. Where is the standard on the continuum between the miraculous and the catastrophic?

The question of quality of care has not been answered definitively, but aspects around the question have been. This is a measure of the difficulties that face all in provision of health care. Much work is at an early stage and it would be interesting to repeat this conference in say five years' time, to review whether nationally there was a more structured approach to the question "Quality of Care - Is It Measurable?"

References

Atwell, J D and Gow, M K (1985) Paediatric trained district nurse in the community: expensive luxury or economic necessity? British Medical Journal 291, 20 July 227-9.

Bond, S (1985) Nursing and measurement. Royal College of Nursing (Fifth Winifred Raphael Memorial Lecture).

Brenner, R (1985) Setting standards. Nursing Times 81, 6 Nov 26-8.

Boswell, D (1986) The development of a quality measurement system for a UK bank. In Moores, B. editor, Are they being served? Oxford: P Allan.

Central Health Services Council (1959) Welfare of Children in Hospital. HMSO (Chairman: H Platt).

Committee on Child Health Services (1976) Fit for the Future. 2 vols. HMSO (Chairman: S D M Court).

Consumers' Association (1980) Children in Hospital: a report on the extent to which hospitals have implemented DHSS recommendations since the Platt Report.

Department of Health and Social Security (1971) Hospital facilities for children - meeting the training needs of HN (71) 22. DHSS (Staff Training Memorandum 59/71).

Kings Fund Centre (1981) Ward sister preparation: a contribution to curriculum building. KFC (KF Project Paper 36).

National Association for the Welfare of Children in Hospital (1985) NAWCH Charter for children in hospital. Journal of the Royal College of General Practitioners 35, April 206.

Townsend, P (1974) Inequality and the Health Service. Lancet 1, 15 June 1179-90.

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1984) Code of professional conduct for the nurse, midwife and health visitor. 2nd ed. UKCC.

USING THE SERVICES

by Jenny Hirst

I have two children - a son, Martin, of 18 and a daughter, Beverley, of nearly 17. Beverley has had diabetes since she was 5 years old.

I would like to say at the outset that in my own area the services for people with diabetes and, to some extent, children with diabetes have improved but I know from my involvement with the British Diabetic Association that many areas are still reporting and recounting similar situations to those my family have experienced over the years.

Why is childhood diabetes a good topic for today? I don't want to go into details of what diabetes is - although my twelve years' experience has taught me that some of the people one thinks should know, don't always! Children with diabetes have insulin injections, have a carbohydrate-controlled high-fibre diet, have to monitor their blood sugars at home and act upon the results. Therefore diabetes is a chronic condition with parents acting as mini-doctors, mini-nurses, mini-dieticians and mini-educators, but it also gives rise to acute situations, such as severe hypoglaecemia where immediate treatment is necessary. The child, however, is still a child and suffers from the usual childhood illnesses which put the diabetic control off balance. They are also admitted to hospital for other conditions - tonsils removing etc.

You can see, therefore, why diabetes is a good topic for today. We need to use the hospital services and the community services, although we as consumers do not see such a division - we see our needs. We need medical services in hospital, medical services at home, education in order to treat and look after our children, and support in order to cope with the stresses and conflicts which arise from having a child with a chronic condition. The fragmentation, rigidity and actual lack of some of the services is glaringly obvious to me as a consumer so I decided to precis our life with diabetes so that the fragmentation, rigidity and needs will be glaringly obvious to you.

Beverley was admitted to hospital at the time of the diagnosis. I couldn't stay in hospital with her as there were no facilities. I'm sure I don't need to convince you of the necessity for mothers to be able to stay with their children. Suffice to say that to have your child diagnosed with a permanent condition and to leave her in hospital for the first time is a traumatic experience in itself. This still happens today.

Beverley was lucky she happened to be diagnosed when the paediatrician with the most knowledge of diabetes was on duty. She could have been diagnosed when the best man for asthma was on duty. This sounds ridiculous as it is but it is a frequent problem for families to request to change consultants when they find "the other one is better for diabetes." I'm happy to know that the British Paediatric

Association have recently brought out recommendations that each Health District should have a designated paediatrician with an interest in diabetes and this would help to alleviate many of the problems.

Beverley remained in hospital for two weeks during which time diabetes was explained, the diet was explained, how to deal with hypo- and hyperglaecemic attacks was explained, how to do injecions was explained and I practised into an orange - not a leg. This was all highly efficient and nothing was left out except the apparent lack of understanding that I was in a state of shock and actually absorbed very little of this information. This, of course, I discovered later.

However, I proved I could do an injection into Beverley and we were sent home with all our kit: insulin, industrial spirit, big glass syringes, big blunt needles - not at all like the ones we used in hospital. Although, of course, the DHSS have recently solved that problem for us. Home! One feels this should have been a happy time with the family all together again but it was only then that I realised how little I knew and how frightened I was. So who was there to turn to? Answer: no one, except a card with a clinic appointment three weeks hence. We struggled through our change of lifestyle, the injections, the diet and the resting - all on our own.

I'm happy to say that many areas now have community-based specialist nurses who visit home and help with the treatment. This also gives the parent a chance to ask all the questions which arise once you actually start looking after your own child at home. But not all areas have specialist nurses and not all areas have enough for the size of the population.

Beverley returned to school and I had to explain to the teachers about diabetes, about mid-morning snacks, about signs of hypoglaecemia. This is all very difficult when you actually know so little and are in danger of looking like an over-anxious parent - which you probably are - and so run the risk of the information being ignored. I felt sure that I shouldn't be the person to be doing this. Surely someone with more knowledge and less panic should be doing it. But who was there? Now, where there is a community specialist nurse she will often go into the school but where there is no community nurse who else is there? The practice nurse from my GP's surgery? I never had a visit from anyone attached to my GP's surgery, including our GP. The district nurse? I never saw one. The school nurse? In my experience there is no contact with the parents of a child with special needs. Furthermore the only contact I have had has only emphasized the lack of availability.

The school nurse system does not seem to work. On one of the very few occasions when Beverley had a hypoglaecemic attack at school which she was unable to handle herself I was never contacted, the GP was never contacted, the school nurse was not contacted, and her teacher took her name and left her with a friend who, fortunately, had a large degree of common sense. It would help Mum so much if she could at least relax while the child is at school in the knowledge that proper care and attention would be given in an emergency, even if that proper care was only the nurse contacting Mum. Unfortunately this so often is not the case and school merely increases anxieties.

After four months of diabetes Beverley had tonsillitis and her diabetes went way out of control with very high sugar levels and ketones. This, I have been told, was a warning for action. Her paediatrician was on holiday so I went to our GP for help and advice. I received what I now class as the standard answer, "You know more about your child's diabetes than I do, so do what you think." I did. I increased the insulin and I increased the number of injections. We got through with no help or support but a great deal of anxiety. The best one can say is you learn by your mistakes and hope that the results are not damaging. I think this was when I first realised that really we were on our own with our problem and when I felt angry enough to fight for a better deal for families with a child with diabetes. I wondered how less able families cope.

Some months later it was agreed that Beverley was not hearing well and she was admitted to hospital for her adenoids removing and grommets. She was admitted to the ENT ward where obviously there was no chance of staying with her. I can only say that this experience was horrific. The knowledge of diabetes of the nursing staff was non-existent. The meals were not just inaccurate in terms of carbohydrate value. There was no carbohydrate at all because I was told, "She is diabetic and on a diet."

I found my husband was popping into the ward on his way to work just to be sure Beverley was "OK" and each evening when we left her we were more upset and fearful than she was as we could have no confidence in the staff and their knowledge of childhood diabetes. The suggestion that we should move her to the Children's Ward twenty yards down the corridor where they were able to deal with childhood diabetes was unheard of. It seemed like too sensible a suggestion for the system.

Prior to home blood monitoring Beverley had quite a lot of hospital admissions often in emergency following a hypoglaecemic attack in the early hours of the morning. We quickly learned that if we called our GP he only sent her to hospital so we by-passed him and used to take her directly to Accident and Emergency. We usually had a hypoglaecemic, vomiting child who had just had convulsions and we came to know from experience that an intravenous injection of glucose would usually solve the problem. I fully accept that the doctor is in charge and responsible but in the absence of any cohesion in the system like finding her notes, contacting the Children's Ward where she was known, a little chat to the parents might have helped. But her treatment varied from investigations into whether her fits were epileptic to "I don't know why you brought her." As a result of our own experiences and those of fellow parents I had a meeting with the consultant in charge who agreed that in future when a child with diabetes entered the Accident and Emergency a doctor from the Children's Ward would be called in, but it should not be necessary for parents to have to go to these lengths to receive proper care and attention for their children.

My final concern about hospitalisation is adolescence. It is obviously wrong that adolescents should be in a ward with young children. It is equally wrong that they should be in an adult ward - the obvious example being an adolescent diabetic in a bed next to an older diabetic who has just had his foot amputated. Complications such as these are realities with which our children have to learn to live but surely they should learn about them gradually, naturally and caringly. A section of a ward for young people would answer the needs fairly simply.

I hope you will see from what I have said that the stresses and strains on the family with a child with a chronic condition can be tremendous, not just at crisis times but in day-to-day living. Diabetes is with us 24 hours a day, 365 days a year, every year with no relief or break for the parents or brothers or sisters. The medical team do the relatively easy part, we amateurs the difficult part - we live with it.

After diagnosis there is the grief period, the mourning of the loss of your healthy child, the guilt mothers feel, the change in life-style, the sibling rivalry, the mental conflict - I could go on and on from the heart. Support and help is needed both at diagnosis and at varying times of the child's development, such as puberty - puberty is bad enough but puberty and diabetes is hell for all the family. There appears to be no help in this way and I am unclear as to whether anyone has even recognised and acknowledged the need. Each family will vary in its need for support but a good counsellor would recognise this and confront it. A doctor in a white coat or even a community nurse in a uniform is, for the parents, hardly conducive to discussions of an apparently non-medical nature even if these people had the necessary counselling skills and the time.

At this point you may well be thinking that these are just the experiences of one Mum and, of course, you would be right. You could also be thinking that my experiences happened up to twelve years ago and things have changed - but you would be wrong. You could have invited any Mum of a child with diabetes to talk to you today and received the same sort of story - some better, some worse. But you invited me.

I am Chairman of the Membership and Branches Committee of the British Diabetic Association. I serve on their Children's Committee and and I serve on their Patient Services Committee. In these capacities I meet parents from all over the country and listen to them. The reason I am still such an active member of our Association twelve years after my daughter's diagnosis is that parents now are still telling me the same stories. So you haven't been listening to just my story.

As a consumer I don't have to worry about how the services are provided, and as Yorkshire woman I can be blunt in my conclusions.

Children in hospital should always be treated in a Children's Unit and should be admitted through that Unit - not Accident and Emergency.

There should be better liaison between the hospital medical team and the general practitioner and his practice staff.

There should be support services in the community working closely with the hospital team and the general practitioner.

My final words are a quote from a letter I recently received from the Diabetes Day Care Centre in Aylesbury.

> If we treat you, we help you today.
> If we teach you, we help you for a lifetime.

For parents of children with a chronic condition I would like to change that slightly.

> If we treat you, we help you today.
> If we teach and support you, we help you for a lifetime.

ASSESSING THE HEALTH SERVICE NEEDS OF CHILDREN AT HOME AND IN HOSPITAL

by Margaret Stacey

In listening to the discussions today I have some sense of déjà vu because so many of the arguments seem to be ones that we had among ourselves as mothers and researchers many years ago, around 1959. Issues have arisen which I and my colleagues were working on in the two studies of children in hospital way back in the sixties. (Stacey Ed. 1970; Hall & Stacey Eds. 1979). I have had to remind myself that at least mothers can walk into wards with their children now, which wasn't possible then. However, it is worrying how many of the same problems that arose then still arise nowadays.

I have been asked to talk about how to assess the needs, the health needs, of children. This request comes to me as a researcher but in the case of children in hospital my researches came out of my maternal role. Whether we are providing services or researching them, the first question that we have to ask about the health needs of children, about the quality of care, is: "What is health work?" If we think of health work as a whole we can then keep in mind the wider ramifications of our own particular involvements whether as politicians, administrators, or professionals. There are four aspects to health work: the first is to promote health; the second to maintain it; the third to restore it, should we by mischance lose it; and the fourth to ameliorate those conditions (such as diabetes which we have just been hearing about) which are not curable.

Sometimes I also talk about, "Who are the health workers?" That is not my intention today. However, let me just point out that in terms of health promotion and health maintenance, unpaid health workers are among the most important. In terms of restoration and amelioration, as you've just now heard, the unpaid health workers rate very high. I prefer in this context to call the mothers and fathers (and it is mostly mothers but also fathers who do this work) health workers, rather than amateurs or parents or untrained. They are health workers and to call them such gives them some status, some recognition of their work in the health care division of labour. If professionals gave parents and guardians rights as health workers then they would not feel quite so stupid when the GP says to them, as does very often happen, "Well, you know more about it than I do." Parents would then recognise their knowledge as valuable, and valuable enough to be joined with that of appropriate professionals. Those of us who are not medically qualified do have knowledge - experiential knowledge, the knowledge from experience. As such this knowledge is valuable in its own right and we do have to ask professionals to listen to what we know.

If we then look at some of the different aspects of health work, what are the health needs which relate to each aspect? For health promotion, a healthy environment is really very important both in terms of home, school and outdoors. I know the NHS as such is not responsible for it all but the NHS has to pick up the pieces left by unhealthy environments, the accidents, the effects of pollution for example. Who else can transmit the information about the effects of unhealthy environments better than the NHS and the professionals who work in it? I also like some of the ideas that the WHO EURO (the European Region of the World Health Organisation) are promulgating. For example, their campaign for health-promoting schools, where really the whole school environment is designed to promote the health of the children, not just to deal with health crises and prevent accidents. Questions of a healthy life style, things like diet and air and exercise and rest in the right proportions all come into health promotion, but we must not forget that some people are not in a position to command those things: they are prevented by reason of poverty or a poor environment, for example. In the health service professionals have to avoid blaming and calling feckless those people whose economic circumstances are so bad they are unable to provide a healthy environment and healthy life style for their children. In present circumstances we cannot always as individuals control our own economic situation.

In terms of health maintenance: as well as the activities just mentioned we traditionally think about health maintenance not in those terms but as disease prevention. The detection of preventable diseases is of course a major and important task and immunisation against infectious diseases comes generally under that heading.

When we think about health restoration, we can think about the curative services, both those that are offered at home and in hospital. I did hear a complaint this morning that there had been too much talk about hospitals and not enough about other aspects. Let us not forget about all the healing work that goes on outside hospital.

When it comes to amelioration, the fourth kind of health work, there is the question of detecting handicapping conditions. I think that when people in the NHS think about it, they tend to put disease prevention and detecting handicap all together under "surveillance". However, in terms of thinking about what the children need and what one has to offer, it is just as well to separate those things out. Preventing disease is one thing; detecting handicap is another. Having detected handicap or diagnosed a chronic problem, the question of amelioration and care arises. The ameliorative activities are most important once the diagnosis has been made; no point in diagnosis if service does not follow.

Turning to research about child health needs, what is being done and who is doing it? Under that heading let me refer to the overviews of research in child health care which Sheila Roche and I have been doing for the DHSS. We have already done two which are now published by the DHSS. The first was an overview of research on the provision and utilisation of child health services from 1979-84. This reviewed all the research that we could trace from the time when Mildred Blaxter (1981) finished her data collection on child health. We persuaded the Department that they needed to have this information continually if they were going to know where to put their research money or if any of the rest of us in the community were to know where to put our research efforts. Update 1 was published in March 1986. Update 2 will be presented to the Department of Health in April 1987. We are also currently working on an overview of research on children in hospital, which has been much in demand. It will be in the hands of the DHSS in September 1987.

The main headings of the classification that we used for the research that was being done are shown in Table 1. These headings indicate what people are finding out about. The question to ask is, are they finding out the right sort of things in the right kind of way to help the proper planning and provision of child health care?

As Table 1 shows, the utilisation of pre-school services well tops the list. Remember this covers only child health care in the community. The table indicates the number of works that we found; it indicates the amount of attention that was paid to these topics. In 1984 the researches covered a five-year period; in 1986, a 16-month period and in 1987 a 12-month period. Given the changes in time span covered, proportionately more research attention is being paid to child health in the latest period. So that's good news. Most research still focusses on the utilisation of the pre-school services and the evaluation of methods of surveillance. In 1986 we found a great deal of attention paid to professional roles in child health care; that has declined a little bit now. However, what has declined a great deal are researches into the school health services. This is interesting in relation to discussions at this conference. Clearly there are particular needs that children have in school, such as we have just heard about. Also there are health hazards in the school environment as such. Furthermore, as I have suggested, the school environment can be health promoting when health care professionals, teachers and parents find a way to work together to that end. But somehow people are not currently doing any research about that. The interest in services for the handicapped is maintained and more attention is being paid to evaluation of services for special needs.

Those are the main headings. Table 2 shows some of the detail within the heading 'Utilization of pre-school services' and now that is changing too. 'Parents' role in child health care,' which includes the mothers' experiences, is a heading which has had to be added. This suggests that the parents' role is being looked at a little bit more. For the first time, I'm very glad to say, children's attitudes to services and professionals is included. Although there is only one entry, we felt that it was so important, a conceptually different category (linked with what we heard this morning about children's rights), that it was important to flag it. Otherwise details are in Table 2. Apart from the children's attitudes there is no research there about experiences of the children or their parents. The focus is on "Do they come?" or "What do they think about us, the professionals?"

Turning to the detail of research into evaluation of methods of surveillance (Table 3) this receives a good deal of attention. Immunization uptake is still the most important subhead here. There has been some change: evaluating screening methods for specific defects is receiving relatively more attention now.

Professional roles (Table 4), as I said, had this enormous buzz in the years between 1984 and 86; that has dropped a little bit. In my view the 'buzz' was associated with professional anxieties about reorganization. The tendency in a reorganization is to go at the problem from the point of view of particular professionals, be they GPs, health visitors, or any other particular category, asking "What do we do?" An alternative would be to ask, "OK, there's a reorganization going on, so what really is it that children need? How can we provide it? Can we do best on our own or with somebody else?" Right now the professional-centred approach has declined a bit.

With regard to the school health services (Table 5), the total number of researches has fallen as I have said: research on the evaluation of screening in school health has fallen right away, people must think they have made their mind up about it; the role of professionals in school health is not receiving attention just now, a problem reflected by the last speaker; illness among school children is not of much interest either; a small amount more attention is paid to health education. However, the few current researches about school health is the dominant feature of this table.

Now we come to services for the handicapped (Table 6). Research into provision and utilization of services still comes top; research on newborn screening has declined a good bit; that on genetic counselling is more or less the same. However the focus of the research papers falls on provision and utilization of services.

Looking at the evaluation of services for special needs (Table 7), we see that the two categories 'parent-held child health records' and 'home accidents and family circumstances' have yielded nothing this time round. Researchers have focussed mainly on child psychiatric services and services for young people. You have already heard that the latter is an important area.

In the bibliographical part of the Overviews, articles are cross-referenced when they apply to more than one heading. This gives some indication of the way researchers relate to other topics of study in child health. There is one point to be made about these overlaps between research papers, namely that there really are very few. People who are working in one of those areas tend just to work in that area. Researchers see the connections, work on the connections between the provision and utilization of pre-school services and professional roles in child health care and to some extent between utilization and evaluation of methods of surveillance. But there is little overlap with other areas. Researches about services for the handicapped are frequently cross-referenced to those on children's special needs, but hardly to anything else. The researches, one might say, reflect the fragmentation which has been referred to so often today. But it is almost more than that: pockets of professional expertise seem to develop and the information does not seem to flow between them. People in writing their papers (which are of variable goodness in terms of methods) do not seem to contextualize what they are doing. That is to say they do not relate it to the total life of the child, the body of medical or nursing knowledge, or to its social context. Each paper appears encapsulated in its own concerns. This has rather worrying consequences in practice, for example associated with the kinds of experience that the last speaker mentioned, which are not unique. She pointed out how professionals who had to deal with one aspect of her child appeared ignorant about other aspects. Parents are surprised at this, suffer a loss of confidence and may become frightened. This lack of ability in practice to contextualize a child's problem also shows in the way the research is done, as revealed by the way the papers are cross-referenced, and the frequent lack of contextualization. It will be interesting to see later this year how researches on children in hospital compare with those on child health care in the community.

So far as the latter is concerned, what is striking (as we pointed out to the DHSS, whom we were advising about where the money for research should go) is the way in which people are blinkered in what they are doing, not only within their own profession but within their particular specialism within their profession. There are barriers to collecting the appropriate data for the proper provision of services to meet children's health needs. These barriers derive from boundaries created by institutions, boundaries created by the professions and boundaries created by the disciplines. There is furthermore an historical legacy: the tension between general practice and the local authority provision of child health care in the community, which is three quarters of a century old, was bubbling over in those large numbers of papers on professional roles we recorded. The form of the institutional boundaries and the professional boundaries can really only be explained by the historical legacy. So we have to think about and we need research about where we have come from as well as what we are doing now in order to decide where we are going or ought to go.

In our first Overview we supported an idea which had come from Children's Division C, I think it was, in the DHSS saying that they would like to have an institute for research into child health care. Our evidence suggested that it was a very good idea. We also suggested that such an institute should be located right outside any existing institutions. The paediatricians wanted it under their control and this we argued would not be the right place, because although they deal with children they do not deal with all aspects of children. We did not want such an institute to get tangled into any internecine warfare. However there is no chance, until government research policy is changed, of getting such an institute. So in Update 1, being realistic, we recognised this and made an alternative proposal. We suggested that what would help to solve the problems that these Overviews reveal, and help to draw practitioners' attention to ways of solving problems, would be to do <u>child-focussed research</u>.

Although we found some few child-focussed researches, children seemed to us to be the focus that was mostly missing. Now it is the case that I have heard that surgeons, when they are asked to help design a new operating theatre, always recommend one ever so like the one they trained in. It has to be said that the first health care research I ever did was child-focussed work on children in hospital. Maybe like the surgeons I'm stuck in my early training experiences. However, be that as it may, I do think the original idea, that you can only really see how a service is impinging upon people if you actually look at it through the eyes of those people, is a fair point. I would want to go further than I did in my original hospital researches where we were justly criticised for treating the children as objects rather than as people in their own right. With the very small pre-school children that is a bit difficult - to learn from the children as people, but you can quite soon start involving them. In the second round we did do that with the children who were between eight and nine years old and also the adolescents.

So when you think about it, it seems to me that one does want to think of the child as the focus, in the centre of the services, as Diagram 1 suggests. This is alternative to the focus on the point of view of the GP, the paediatrician, the health visitor, the manager or administrator. It is the case that managers and administrators can see across the board in a way that those who are practitioners in a particular area have greater difficulty in doing. It is true because it is their business; it is a managerial matter to put the things together. We had a very good model this morning. But nevertheless those people still have a vested interest in managing or administering, so although their view may be broader it may still not necessarily, unless they consciously make it that way, be from the bottom up, that is child-focussed.

If you think about the child at the centre of the service, as the focus, you see various health workers all the way round. What is most important, you can see also the way those people need to work together for the child, how they impinge on that child and of course also on that child's parents, who are being its particular carers. The diagram shows some of the numbers involved: the mother and father, the midwife, the health visitor, the general practitioner, the district nurse, the emergency services. Yes, I know some mothers never see some of them, but they are supposed to be there and they are on paper in the plan. Mildred Blaxter pointed the finger at the emergency services in her children's health book in 1981. In our Overviews we did not find work that was looking at the emergency services. They were mentioned again today. The lack of support that parents may experience in an emergency is worrying. Proper support requires the coming together of many parts of the service, many people: the outpatient department and within it specialists and nurses and all of the other people including the X-Ray, the path lab. (I apologise for calling them 'et al,' but I was running out of space.) Voluntary agencies come into it, the inpatient services, and again we have the specialists and the nurses. The social worker may well come in, all of those people, but research on that is missing.

In order to get data about the impact of services on the child, interdisciplinary and cross-professional research is essential. One person on their own cannot do it without the cooperation of others. I think it would be very helpful if a number of health authorities (a few have it in their minds and one or two are doing it) were to deliberately set up interdisciplinary research with different health care practitioners and various other kinds of scientists, like psychologists, sociologists, or economists for example - whoever is relevant to the particular problem. There is a real possibility for health authorities to do child-focussed research. We have indicated the DHSS should be encouraging it: multidisciplinary, inter-professional, so we can see what the service taken altogether looks like from the child's point of view.

References

Blaxter, M (1981) The Health of the Children: a Review of the Place of Research in Cycles of Disadvantage. London: Heinemann Educational Books.

Hall, D and Stacey, M (Eds) (1979) Beyond Separation: Further Studies of Children in Hospital. Routledge & Kegan Paul.

Roche, S and Stacey, M (1984) Overview of Research on the Provision and Utilization of Child Health Services. London: DHSS.

Roche, S and Stacey, M (1986) Overview of Research on the Provision and Utilization of Child Health Services, Update 1. London: DHSS.

Roche, S and Stacey, M (1987) Overview of Research on the Provision and Utilization of Child Health Services, Update 2. University of Warwick: DHSS.

Stacey, M (Ed) (1970) Hospital, Children and their Families: A Study of the Welfare of Children in Hospital. Routledge & Kegan Paul.

TABLE I

Distribution of entries by main head: 1984, 1986 and 1987 compared

		1987	1986	1984
I	Utilization of pre-school services	66	44	96
II	Evaluation of methods of surveillance	50	35	65
III	Professional roles in child health care	34	54	48
IV	School health services	11	24	32
V	Services for the handicapped	29	31	35
VI	Evaluation of services for special needs	48	45	33
	Total entries	238	233	309

Source: Roche & Stacey, 1987

TABLE 2 Distribution of references by sub-head

I	Utilization of preschool services	1987	1986	1984
Ia	Provision and use of services in relation to infant and child mortality	5	6	10
Ib	General surveys of use of services in relation to morbidity	10	8	20
Ic	Attendance for developmental assessment	8	4	10
Id	Parents' attitudes to child health services	18	10	25
Ie	Reasons for attending child health clinics	8	5	8
If	Parents' role in child health care and their experiences of their children's symptoms in relation to consultation behaviour (1)	10	4	14
Ig	Service monitoring	6	7	9
Ih	Children's attitudes to services and professionals (2)	1	-	-
	All I	66	44	96

(1) Category modified from previous one which was 'Mother's experiences of their children's symptoms in relation to consultation behaviour, especially of GPs'.

(2) A new category.

Source: Roche and Stacey, 1987

TABLE 3 Distribution of references by sub-head

II	Evaluation of methods of surveillance	1987	1986	1984
IIa	Immunization: surveys of uptake, administrative procedures and attitudes of parents and professionals	19	12	24
IIb	Immunization: pertussis and rubella	7	7	11
IIc	Evaluation of developmental screening in general practice and in the child health clinic	6	6	16
IId	Evaluation of screening for specific defects	18	10	14
	All II	50	35	65

Source: Roche and Stacey, 1987

TABLE 4 Distribution of references by sub-head

III	Professional roles in child health care	1987	1986	1984
IIIa	GP involvement in comprehensive child health care	5	11	9
IIIb	Management of acute illness in general practice	2	5	5
IIIc	The role of the health visitor	20	30	23
IIId	Interprofessional collaboration	7	8	11
	All III	34	54	48

Source: Roche and Stacey, 1987

TABLE 5 Distribution of references by sub head

IV	School Health Services	1987	1986	1984
IVa	Evaluation of screening in schools	3	15	17
IVb	Professionals in school health	1	4	9
IVc	Illness among school children	4	1	6
IVd	Health Education in Schools	3	4	0
	All IV	11	24	32

Source: Roche and Stacey, 1987

TABLE 6 Distribution of references by sub-head

V	Services for the handicapped	1987	1986	1984
Va	Provision and utilization of services	21	18	18
Vb	Newborn screening for handicap	2	8	11
Vc	Genetic screening and counselling	6	5	6
	All V	29	31	35

Source: Roche and Stacey, 1987

TABLE 7 Distribution of references by sub-head

VI	Evaluation of services for special needs	1987	1986	1984
VIa	Support services for mothers (3)	6	8	7
VIb	Infant feeding	3	10	5
VIc	Parent held child health records	0	1	5
VId	Home accidents and family circumstances	0	4	5
VIe	Child psychiatric services and services for those with developmental delays	15	8	5
VIf	Services for young people	19	11	3
VIg	Child health professionals and non-accidental injury	2	3	3
VIh	Care of children with particular disorders (4)	3	-	-
	All VI	48	45	33

(3) Modified from 'Support Groups for mothers'

(4) A new category

Source: Roche and Stacey, 1987

MISSING:

THE CHILD FOCUSSED RESEARCH