

TERTIARY SERVICES FOR CHILDREN IN SCOTLAND
REPORT OF THE ‘PLANNING THE FUTURE’ CONFERENCE

11 JUNE 2004

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1. INTRODUCTION

SPEAKER: PROFESSOR GEORGE YOUNGSON, CHAIR, SPECIALIST SERVICES SUB GROUP, CHILD HEALTH SUPPORT GROUP

TERTIARY SERVICES FOR CHILDREN IN SCOTLAND PLANNING FOR THE FUTURE

Tertiary services are delivered in the main from the four university hospitals, making Scotland almost completely self-sufficient in tertiary care. The service is dependent in many specialties on a small number of carers with a direct relationship between the caseload and the number of service providers. Some services, therefore, may disappear and so preparation and planning is needed to meet the daunting changes facing the service over the coming years.

The small workforce numbers means secure planning in service delivery models and solid succession strategies are needed. Solutions will clearly include collaboration between clinicians and hospitals on a scale not previously seen or required.

The service needs to be sufficiently flexible and responsive to cope not only with the changes, but also to accommodate and provide improvements and advances in treatment.

The Child Health Support Group aims to act as a catalyst of change and is responsible for bringing forward the agenda set by health planners in the Scottish Executive. Wide consultation with service providers, patients and their families is required.

Some of the challenges facing services include:

- The need for increasing specialism within a shorter period of specialty training
- New legislation defining working times and conditions
- The availability of the consultant workforce
- The need to develop an adequate work-life balance to boost recruitment and retention of staff
- Public expectation that services will be accessible, equitable, of international standard, and delivered by people who know what they are doing
- The small number of cases (in relative terms) services deal with
- The number of carers and the problems that causes when trying to provide continuity
- The falling birth rate in Scotland
- Changes in children's diseases – cancer in childhood is increasing, respiratory diseases in childhood are increasing, obesity in children is increasing causing higher rates of diabetes and sleep related apnoeas.

The Child Health Support Group has embarked on a review of tertiary services. In the first phase, four pilot studies have taken place and the results of those and recommendations from them were presented at the conference. In the next phase the Group will be to look at all the other tertiary services; at the interface between tertiary and secondary care and the other institutions involved in training and education; and at the interdependency there is in tertiary paediatrics with other specialties such as radiology and pathology and neonatology.

In essence the conference was about sharing the work that has been done to date and listening to responses. The information gathered from the conference, and reported in this document, highlights the experiences of some tertiary services already informally networked throughout Scotland, and of services in other parts of the UK. Defining the problems should lead towards the solutions.

The pressures are real and current. The service is being sustained often by individuals and often in a

way that often at an individual level in a way that bears little resemblance to what is in contracts or administrative documentation. That situation is undesirable and unsustainable in the long term. The best and most effective alternatives need to be explored.

2. SETTING THE SCENE

SPEAKER: MALCOLM CHISHOLM, MINISTER FOR HEALTH AND COMMUNITY CARE, HEALTH DEPARTMENT, SCOTTISH EXECUTIVE

There are many challenges in improving Scottish children's health. There are worrying trends in health-related behaviour, for example, the amount of fizzy sugary drinks consumed by children and young people, the level of alcohol and tobacco consumption and the amount of exercise taken.

Demographic trends mean that the number of children is expected to drop from almost 1,000,000 at the turn of the century to just over 750,000 by the year 2023. Use of health services has also changed with, for example, a 20% reduction in children requiring surgical interventions between 1997/1998 to 2002/2003.

In contrast, there have been significant improvements in health care: for example, cancer five-year survival rates in children has improved from 50% in 1975-1979 to 76% in the years 1995 to 1999, and continue to improve. These advances create their own challenges and have significant implications for other services, for long-term monitoring and follow-up.

In response, the Scottish Executive is committed to:

- Ensuring that every child in Scotland has the best possible start in life
- Improving child health, welfare and opportunity
- Delivering world-class services for children of all ages.

Policy and strategy context

Through the Partnership Agreement which sets out its priorities, the Scottish Executive is committed to providing opportunities for children and young people of all ages. A Cabinet Delivery Group for Children and Young People, with senior Ministerial representation, including the Minister for Health and Community Care, has been established to make sure this vision is realised.

Key policies and strategies include:

- The joint planning guidance for children's services, issued by the Scottish Executive, setting out how local agencies will be expected to develop integrated services for children
- The child protection reform programme which has issued a Children's Charter and Standards Framework
- The joint inspection system for child protection, leading to joint inspections across the NHS, local authorities and police for children's services in general
- Towards a Healthier Scotland, which outlines key activities for early years and teenage transitions
- The Integrated Early Years strategy provides an integrated framework for the provision, planning and commissioning of early years services
- Health for All Children which sets the framework for delivering services at Primary Care level.

The Scottish Executive's goal is to set up multi-faceted, integrated services, bringing together childcare, pre-school education and healthcare services. The role of parents is crucial and parallel support services for them, which include advice on health promotion, counselling and support for their role as parents, are an integral part of the vision. This will help to provide the best start for all Scotland's children and an important route to identify children and families who may need more specialist, targeted support to meet their particular needs, in the short term and long term.

The development of Community Health Partnerships will help the integration of services. These Partnerships are designed to give patients and staff a greater say in how their health services are delivered. The Partnerships will be responsible for planning and delivering community health

services such as GP services, pharmacy and community nursing.

Child Health Support Group

The Child Health Support Group was established in 2000 to work with Scottish Ministers and the NHS to drive forward improvement in child health and child health services.

It started work by visiting all NHS Health Board areas to gain an overview of the strengths and weaknesses in children's health services. It then produced a child health Template for NHS organisations to use as a framework for the planning, provision and monitoring of child health services.

The main areas of weakness in child health services identified during the visits are now being addressed by the Child Health Support Group. These themes are:

- Specialist paediatric services
- Integrated working
- Community-based child health
- Child and adolescent mental health
- How best to involve children and young people in the design of services for them.

Pressures on tertiary services

The range of pressures on specialist services currently include demographic trends; recruitment and retention issues; the impact of the European Working Time Directive; the need to balance local access and increasing specialisation; the need to integrate services across health, social work and education; the changing pattern of disease; the impact of new information and medical technologies; and increasing public expectation.

Because its geography and the number of its children, Scotland faces particular challenges in providing and sustaining child health services.

The specialist services sub-group of the Child Health Support Group, chaired by Professor George Youngson will be making recommendations about acute specialist paediatric care in Scotland based on the pilot reviews it has carried out and on the proceedings of the conference (reported in this document).

Other key developments that will support this work include:

- The National Framework for Service Change in the NHS in Scotland

An expert national advisory group, chaired by Professor David Kerr, is currently considering how best to provide sustainable health services in Scotland, building on the themes of integration, redesign and reconfiguration established in the Partnership for Care White Paper.

The group will produce a 'National Framework for Service Change in the NHS in Scotland' by March 2005. The group will examine and define the future requirements for health care in Scotland and make proposals for how to plan – at national, regional and local levels – to meet the challenges and maximise opportunities.

The Framework will look at all aspects of the health service in Scotland, from services delivered in local settings to highly specialised care. It will also consider the patient journey, looking, for example at how the service needs to organise itself to meet the needs of children or of older people. The work will provide a context within which the service can work towards some clear and shared vision of the future. But it will also set out practical guidelines for service improvement.

Other aspects which fall under the group's remit are:

- Demographic and epidemiological trends as they impact on health care for children
- Opportunities to deliver care for children – particularly those suffering from chronic diseases – closer to home
- The patient's perspective/needs as the driver for service change – what kind of services will Scotland's children require in the future and how the Scottish executive and the NHS plan now to ensure that they are provided?

Development of the national framework, is taking place in conjunction with work in other areas. For example, work around how to plan and deliver unscheduled care more generally has a particular strand that links to parallel work on unscheduled care for children, being undertaken by the working group established to review emergency care for acutely ill and injured children, chaired by Dr Tom Beattie.

Similarly, the findings of the Child Health Support Group sub-group on specialist services will feed into the development of the National Framework for service change. Children's tertiary services have been chosen specifically as one of two areas (the other being neurosurgery) for detailed planning and mapping, looking carefully at the options for the future shape of the service in Scotland. A short-life working group will be convened to consider how to ensure long term, high quality, and sustainable tertiary paediatric services in Scotland.

- Workforce issues

The Scottish Health Workforce Plan 2004 Baseline is designed to:

- Improve current knowledge of the health workforce and future projections
- Support effective workforce planning and decision-making
- Guide key alliances with partners in education and employment.

This report will become an annual publication by my Department's National Workforce Committee.

The European Working Time Directive is also driving service redesign.

The UK policy on Modernising Medical Careers sets out fundamental changes to the delivery of postgraduate training for doctors. These changes will improve the quality of services.

Healthcare professionals will have the opportunity to develop their roles to take on responsibilities traditionally considered as belonging to trainee doctors.

- Community Child Health

The Child Health Support Group has also undertaken work, led by Dr. Zoë Dunhill, on community child health. Through work with NHS colleagues, and with members of the Health Department's Women and Children's Unit, guidance was developed on how best to implement the recommendations in the report, Health for all Children produced by the Royal College of Paediatrics and Child Health.

The report recommends a reduced programme of universal surveillance and screening to enable professionals to concentrate their efforts on children and families most in need. The draft guidance was widely welcomed and consultation views are now being considered. Finalised guidance will be issued by the end of 2004.

The Child Health Support Group is also working with NHS Quality Improvement Scotland, who have the lead role, to produce child health standards to improve and monitor the services provided

for children. NHS Quality Improvement Scotland has established a Children's Services Steering Group to drive this process forward.

- Child and adolescent mental health

The Child Health Support Group is taking an active role in implementing the Scottish Needs Assessment Report on Child and Adolescent Mental Health and plans to publish a framework later in 2004 which will support an integrated approach to local planning and delivery of services across the continuum of promotion, prevention and care.

The Group has been reviewing psychiatric inpatient facilities for those children and young people with more severe and enduring mental health difficulties. The Inpatient Focus Group will be reporting in the autumn of 2004.

- Patient Involvement

Recognising equality and diversity is vitally important in health services. The Health Department is developing an integrated Equality and Diversity Strategy in line with the Partnership Agreement commitment. The principles set out in the Fair for All policy are to be extended across the whole NHS. This will ensure that health services recognise and respond sensitively to the needs of individuals.

The views and experiences of children and young people will be actively sought to help develop and implement this policy. The Child Health Support Group will be involved in developing principles for engaging children and young people and ensuring their rights and responsibilities are recognised by themselves and the services they are accessing. This will build on the work already taking place through voluntary sector organisations such as Action for Sick Children.

Announcements

In addition to the vast amount of work taking place currently in Scotland to provide world-class services for children and to help support the excellent work going on in Scotland, four new initiatives will be started:

- New funding of £1.3 million over two years, in the first instance, will be made available to support capacity development in the workforce for children and young people's mental health and well-being. Some of this will be about tackling immediate difficulties in inpatient services. But the Scottish Executive will also be looking to develop capacity 'upstream' – to strengthen capacity for promotion and prevention. Training will be a key foundation for this
- The Child Health Support Group is to develop an overarching framework for action for child health, drawing together the existing plans, policies and strategies.
- The National Framework for Change in the NHS will have a distinct stream of work dealing with the service change required to plan and deliver children's services in the longer term.
- The Scottish Executive recognises the need for clinical leadership for these processes but more importantly to ensure implementation. The Women and Children's Unit will, therefore, bring forward proposals to create a national post to provide this leadership.

3. SECURING THE FUTURE – THE CHALLENGES

SPEAKER: PROFESSOR SIR JOHN TEMPLE, AUTHOR OF *FUTURE PRACTICE* AND *SECURING FUTURE PRACTICE*

In compiling the report, *Securing Future Practice*, the aim was to step back and look at Scotland and examine what was needed for the medical workforce.

The many drivers for change form the backdrop to any examination of service provision. Scotland is only one of two countries in Europe in which the population is falling (Germany is the other) and there has been a fall equivalent to the whole of Tayside disappearing between now and 2013.

A macro economy of sufficient size to be able to redirect and reorganise is required when planning and changing service delivery. To achieve that now will take all 15 health boards working together in collaborative groupings that are genuinely collaborative and co-ordinated.

The profile of the Scottish population is changing and the predictions which is particularly stark and the predictions are that by 2031 there will be many more older people and fewer young people, a situation which will bring its own problems and challenges for healthcare services.

In most parts of the UK people are moving away from the centre. In Scotland the trend is for people to move to the central belt, particularly the young, a process which again will create its own problems for health care provision. In five health board areas the populations are predicted to rise (e.g. Lothian, Forth Valley, Borders, Fife and interestingly Shetland, the latter by only a small amount), but to fall in the rest of the country, in particular the Western Isles where a fall of 17% (or 5,000 people) is predicted. Doctors are also migrating and it is with increasing difficulty that they are recruited to some of the more remote areas.

The report considers four fundamental questions:

- What kind of service do we need to staff?
- What kinds of doctor do we need?
- How do we provide for education, training and career development?
- How do we secure the workforce?

Public expectation is that service delivery will be by trained doctors or, by doctors in training who are properly supervised and act within their competence. Also the public expects that the service should be as local as possible, that is, what can be delivered locally, safely and appropriately. Doctors themselves expect to work differently; those graduating today have a different work ethic from their predecessors and their likely life-style preferences must be taken into consideration.

The service needs to come to accept the demands of the European Working Time Directive. More care workers need to be found and in the UK the drive in, for example, nursing and medicine has been based on recruitment on overseas, a situation that cannot be sustained and in some cases, may be unethical. Scotland needs to 'grow its own'; the process has started but will take seven to 14 years to come to produce significant results. Skill mix another potential solution and currently, service providers try to make sure staff are doing the job they want to and have been trained for and are not doing something that someone else can do. The fundamental problem is that Scotland is short of doctors, particularly trained doctors.

The report *Future Practice* (2002) states: 'The supply of doctors now and in the future will not meet the demand if we retain current patterns of service delivery.' Decisions need to be taken about which which unit, locality, hospital or community will do what. This may mean having three types

of unit:

- The hospital at the hi-tech end of the service where major investigations and treatments take place
- Somewhere for elective procedures to take place
- Even smaller units carrying out day care treatments.

Staff would need to be pooled to meet the needs of these three units. In this model 90% of the patients would still be treated where they would have been treated before; only 10% would move.

The geography of Scotland creates problems not shared in other parts of the UK. The population in remote and rural areas, which is less than 4% of Scotland's entire population, have a right to fair access to services, even if residents accept certain restrictions on access by virtue of the fact that they choose to live in these areas.

Again, in *Future Practice (2002)*, it states: 'Travel time increases risk for emergency care, but so can lack of capacity, critical mass or experience in a small unit.' That still applies, and effective emergency care can only be sustained if a real partnership develops between small and large centres. This also probably means pooling of staff on a rotational basis. Transport services, making the best use of land and, particularly on the west side of the country, water (although this does not mean lifeboats) and air, need to be reviewed.

The kind of doctors required in the service in the future will depend on what they will be expected to do. The critical and defining role of a doctor is diagnosing clinical problems and determining management; that does not necessarily mean performing the treatment or carrying out the various facets of diagnosis.

In the future services will be delivered by trained doctors. Currently in Scotland 38% of all doctors working are in training; even by 2012 this may have been reduced to 30%. Scotland needs a greater number of trained, judgement-safe (i.e. competent in their field of specialist practice including general practice) doctors. A smaller number of trained doctors who are judgement-safe but who have also acquired the additional competencies for more advanced or in-depth specialist care in their field of practice will also be required. In the future the majority of doctors will be judgement-safe, they will deal with common emergencies, be able to stabilise and transfer patients with rarer problems and have a wide range of service ability. But only a small number will train beyond that, determined by service need.

New ways of training doctors will be needed, taking into account constraints, such as the European Working Time Directive. The current training is too long, particularly in Scotland. For example, the average length of time to reach consultant level currently is 14 years, not all of which involves being educated. This length of time needs to be shortened and there are moves afoot to achieve that. The European Working Time Directive will cut down, potentially by half, the number of hours in a doctor's training, reducing the opportunities for learning and teaching. In the document *Modernising Medical Careers*, how trainees can be turned into trained doctors much sooner is considered.

An accelerated system will mean introducing skills training centres. Simulation is an expensive but effective way to train people in basic skills. It also allows trainees to practice in a safe environment that is as realistic as possible, but where there is not the potential to harm people. Having done all that, more must be done to retain staff in the service. That will be helped by service redesign, more effective promotion of the profession is required. The *Securing the Future* report concludes: 'The medical workforce can only be secured by simplifying its structure, through service redesign and by effective national and regional planning. This will deliver the doctors and the service Scotland needs.'

4. THE WELSH EXPERIENCE

SPEAKER: DR HUW JENKINS, DIRECTOR OF HEALTHCARE SERVICES FOR CHILDREN, WELSH ASSEMBLY GOVERNMENT & CONSULTANT PAEDIATRIC GASTROENTEROLOGIST

Wales is in the process of implementing a National Service Framework (NSF) for Children's Services. In February 2001, the secretary of state for Wales stated: 'These steps enable us to launch a new crusade to improve the health of the nation's children ... we will draw up new national standards for children's services, to give every child the best start in life. The lottery in care in children's services must end.'

In fact, the political and strategic drivers behind the process show that children have been quite high up the agenda in Wales for several years:

- Minister for Children in Wales in post since the inception of the NSF in 2001
- Cabinet sub-committee for children & young people
- Children & Young People Partnerships, to try to put into practice multidisciplinary working between health and social care services
- Children's Commissioner
- Director of Health Care Services for Children.

The purpose of the Director of Health Care Services for Children's role is, on behalf of NHS Wales and working closely with professional advisers including the Chief Medical Officer, to lead the drive for innovation and continuous improvement and the development and implementation of service standards and performance management across children's health care in Wales. It is also to provide strategic leadership and be responsible for implementation of children's healthcare strategies and the associated NSF. The Director is involved in four main areas of work:

- NSF
- Tertiary Services (CYPSSP, see below)
- Food & Fitness Task Force
- Ten-year healthcare strategy development.

The overarching aim for the NSF in Wales is that 'All children and young people achieve optimum health and well-being and are supported in fulfilling their potential.'

The NSF has been developed as a partnership by setting standards for health and social care and with close links to education, housing, transport, the voluntary and other stakeholders (including children and young people and parents and carers). It is important to involve all these key agencies, organisations and people if the NSF is to make a real difference to the lives of children and young people.

The NSF has seven modules:

- Improving health and well-being of all children and young people
- Disabled children and young people
- Children and young people in special circumstances
- Mental health and psychological well-being
- Acute and chronic illness or injury
- Maternity
- Medicines.

Wales is currently part of the way through the development and implementation process. It began properly in 2002 with the establishment of the external working group and an extensive period of

consultation with professionals and children and young people. In December 2003 draft standards and key action points were drawn up. At this stage, a quality assurance process took place to assess whether the standards and action points were measurable. The process to combine all seven modules in one document also started after that time, along with the development of a self-assessment audit tool (SAAT), designed to facilitate implementation of the standards.

The NSF started with a submission process in July 2004, prior to a consultation period beginning in September 2004. Redrafting of the document is expected to begin in December 2004 with publication along with the SAAT scheduled for June 2005.

Examples of the style of the key action points demonstrate how they have been drafted to be specific and punchy:

- Universal Key Action

1.14. Children and young people who require services in addition to the universal services have these co-ordinated by a Key Worker. The name of the Key Worker is made known to the child and is recorded in the child's care plan.

- Specific Key Action

6.4 A Children's Community Nursing Team is available to meet local needs in every area in Wales.

Inspection in relation to the NSF will be the joint responsibility of the Health inspectorate Wales, Social Services Inspectorate Wales and education inspectorate (ESTYN).

Children and Young People's Specialist Services Project (CYPSSP)

Scotland seems to be going through what Wales embarked on in 2002. A Tertiary Services Review was carried out which made recommendations for changes in services. This resulted in policy development followed by a Ministerial announcement. The outcome was to pilot standards and a service model for a managed clinical network (MCN) in gastroenterology.

The MCN was based on three principles, all of which had to be married up for the process to succeed:

- Equity of access for all irrespective of postcode
- Management as close to home as possible
- Management by fully trained specialists, using best available experience and facilities.

The definition of an MCN used in the project was:

- Linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated manner, unconstrained by existing professional/Trust/Health Authority boundaries to ensure equitable provision of high quality, clinically effective services.

The desirable characteristics of the MCN include:

- Connection/partnership, rather than isolation/self-sufficiency
- Distribution of resources, rather than central management
- Flexibility
- Clear lines of responsibility to ensure leadership at every level
- Quality assurance, demonstrated in an annual report
- Agreement of health professionals to participate in the MCN
- Patient involvement (an important aspect).

Subsequently, standards for the MCN were developed:

- Children and young people with conditions on the NSCAG list are discussed with a specialist
- Appropriate and timely plans are made for every child requiring specialist review, for example,

immediate in-patient transfer to a specialist centre; an out-patient appointment at a specialist centre; outreach specialist clinic appointment at a local district general hospital

- Specialist care is delivered in a multidisciplinary fashion with adequate staffing to allow seamless continuity of care
- Timely and appropriate communication between specialist services and all other levels of care
- Appropriate verbal and written confirmation for children and young people and families
- Specialist follow-ups as close to home as possible (outreach/transition services).

The project is moving forward to begin development of standards for specialist services where they do not already exist; to develop a service specific model for MCNs for specialist services; and once these stages are completed, deliver these to Health Commissions Wales and local health boards.

Other components of the project include work on care pathways, IT (including telemedicine), training and education, innovative ways of working, and developing a robust audit tool for monitoring. The project's different facets are run by different groups convened for the task, and these include representation from the broad range of professionals and organisations engaged in delivering and influencing services for children and young people in Wales. This includes children and young people themselves and parents. A series of external working groups have this year begun work on key areas of the project including neonatal services, nephrology, oncology (palliative care), gastroenterology and paediatric intensive care units (PICU).

There are perhaps specific issues which apply in Wales that the groups will have to deal with, that may or may not be faced in Scotland, including:

- Links to other tertiary services in England
- The North and South Wales difference: although the project is a Wales-wide initiative, it will be important to work with what is logical for each area
- The need for a political (why this is happening) explanations well as a professional one
- The need to ensure that children and young people and their families are at the centre of service provision.

The major work embarked upon in Wales is all part of a ten-year planning process. It will also include a workforce development group. Success will depend in part on the funding that is available but also the management of patients' and public expectation.

5. PROMOTING CLINICAL EXCELLENCE; ADVANCING PRACTICE, RESEARCH AND EDUCATION; DEVELOPMENT OF THE NEW NURSING ROLE

SPEAKER: JUDITH ELLIS, HEAD OF NURSING, GREAT ORMOND STREET HOSPITAL

Great Ormond Street Hospital is specifically a tertiary centre – it has no accident and emergency department and does not accept GP referrals. Its Inner London site can cause logistical problems, but it is in close proximity to relevant important organisations such as the Royal Colleges and National Children’s Bureau, and University College London’s Institute of Child Health is on-site.

Patients come to the hospitals from all over the UK and abroad:

- London 55.44%
- Eastern 23.16%
- South East 12.87%
- Other GB 3.01%
- Overseas 2.38%.

The Hospital’s income is increasing year on year. The current annual total is around £160 million. This breaks down as follows:

- From Primary Care Trusts which commission services £57.4 million
- For research £27.1 million: Great Ormond Street is a five-star research trust and work now includes investigation of more general child health topics, as well as into the rarer problems
- Private patients £8.7 million: a new private wing will be opened towards the end of 2004.

The definition of a tertiary hospital on which Great Ormond Street models itself is:

- Tertiary hospitals predominantly deal with children with conditions that are rare, intractable, complex, unusually severe, or complicated by other disorders, who are therefore thought to do better if they are referred to tertiary services for diagnosis or treatment.

The Hospital is in the process of taking in the North Middlesex Hospital. All the staff from there will become part of Great Ormond Street and the site will be known as Great Ormond Street at the Middlesex. One of the aims of this is to try to streamline access to Great Ormond Street, so that children do not have to be seen at four or five different district general hospitals before reaching the tertiary centre.

Great Ormond Street’s only focus is children. The hospital does not have targets for waiting times or trolley waits – staff only have to worry about ‘getting it right’ for the children.

The site is home to around 32 sub-specialties which means that children do not have to transfer to other hospitals to receive the treatment they need.

In the year 2002-3, Great Ormond Street saw:

- 11,671 in-patients, with an average length of stay of 2.7 days. The aim is to get the children in diagnosed, started on treatment and out again as quickly as is appropriate
- 91,751 out-patients
- 9,234 day cases
- 12,340 operations
- 24,210 finished consultant episodes (1,731 private).

The hospital has a constant need to find more staff and to get them working differently. This involves establishing new roles to help staff:

- Reach their full potential
- Make best use of their skills.

New legislation (European Working Time Directive and New Deal for Junior Doctors) creates opportunities for other professionals to develop their roles.

Great Ormond Street is a training centre and at any one time has 400 pre-registration nursing students. This means the hospital has to put on many of its own training and education events. It has a smaller number of AHP students. They are post-registration and have come to Great Ormond Street for important exposure to specialist children's services.

Service teams are given money to review services and come up with improvements. Much of this work has involved new role development and some of the new roles include:

- Housekeepers
- Patient environment team leaders
- Modern matrons/senior nurses
- Administrative and clerical staff
- Clinician assistants
- PAL's and child advocates
- Social workers based on-site
- Information staff (a role which includes maintaining a dynamic and frequently accessed website)
- Advanced nursing practice roles
- Nurse consultants: autonomous decision makers who have honed their skills through interdisciplinary education courses
- AHP consultants
- Clinical site practitioners.

Clinical site practitioners are generic, high trained, highly motivated paediatric nurses. Aspects of the role include:

- Assessment/care of sick children: the clinical site practitioners can refer patients into PICU
- Acting as senior clinician for the Trust, leading the night team
- Providing clinical/managerial support for nurses and junior doctors: part of their role involves education and training of sub-specialty staff, for example, in the renal unit when a child is experiencing respiratory problems with which the staff are unfamiliar, the clinical site practitioners will go in and educate the staff in to look after the child
- Providing the full range of intensive care skills, including ECG, ordering investigations, X-ray interpretation, pain control
- Taking the lead on complaints, child protection, resuscitation, major incidents.

An audit of the role was carried out, and it reached two significant conclusions about its benefits:

- Two clinical site practitioners and three middle-grade doctors can provide adequate cover to the paediatric wards at night, provided they work as a team across specialties
- Based on two phases of 28 nights, the likelihood of five staff being required together is five hours in 1,120.5 (one in 225 or 0.004%).

This demonstrates that the new team was working much more efficiently than the previous configuration.

The clinical site practitioners have the 'space' to use their talents, thereby facilitating much more decision making closer to the point of impact. The advantages of this include:

- Speeding up decisions and reaction times
- Releasing creative, innovative capacity

- Increased job satisfaction, motivation and commitment
- Elimination of layers of management.

Another important function at Great Ormond Street is to listen to children, parents and families, to help build choice into the service. The Hospital operates:

- A national patient survey
- Patient Listening and Advice services
- A Family Forum.

This level of communication helps staff to deal with what parents say is their greatest frustration – the seeming lack of integration between different elements of service. It is vital to Great Ormond Street staff that we try to integrate tertiary with primary and secondary care services. One method is to name a lead clinician for a child and family so that they can identify with one person in amongst the numerous staff members with whom they come into contact.

Tertiary centres are essential to:

- Deal with the rarer cases
- Generate a critical mass for research into new ways of working
- Educating specialists and generic paediatricians who can deal with a range of complex cases.

6. OVERVIEW OF PILOT REVIEWS

6.1 PAEDIATRIC GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION SERVICES IN SCOTLAND

SPEAKER: DR MICHAEL BISSET FOR THE SCOTTISH GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION GROUP

Services in this area have changed out of all recognition over the last 10-15 years. The main reasons for this are changes in the spectrum of diseases and number of patients seen.

Examples of these changes include:

- Coeliac disease: the recorded incidence is 1 in 2000 but the real incidence is likely to be as high as 1 in 120. The majority of the 'silent' cases are asymptomatic, but are important to find because they are at increased risk of anaemia, osteoporosis and intestinal cancer. Attempts to screen high risk groups (for example, type 1 diabetic children) are compromised by flaws in screening services
- Crohn's disease: there has been a fourfold increase in incidence over the last 30 years. In Scotland now there are around 90 new cases each year with a total annual workload of around 600 cases
- Children on Home Enteral Nutrition (HEN): 10 years ago few children were on HEN but the development of safe insertion techniques and improved support services has led to a significant increase. Now there are more than 600 children in Scotland known to be on HEN (does not include data for district general hospitals), 50% of whom have neurological handicaps and who are likely to require HEN for the rest of their lives. This is, therefore, an increasing workload for services year on year.

The current configuration of services in Scotland is as follows:

- Royal Hospital for Sick Children, Glasgow, serving a population of 2.5 million in the west of Scotland

2.1 WTE PGHN Consultants

1.0 WTE Specialist Nurse

1.0 WTE Specialist Dietician

- Royal Aberdeen Children's Hospital, Aberdeen, Ninewells Hospital (clinic and endoscopy), Dundee, and a clinic in Inverness, serving a population of 1.2 million in the north of Scotland

1.3 WTE PGHN Consultants

1.0 WTE Specialist Nurse

0.5 WTE Specialist Dietician

- Royal Hospital for Sick Children, Edinburgh, and clinics in Kirkcaldy and Dumfries, serving a population of 1.4 million in the east of Scotland

1.0 WTE PGHN Consultants

2.0 WTE Specialist Nurse

0.5 WTE Specialist Dietician.

Services are delivered by a range of practitioners – consultants in PGHN, specialist nurses, paediatric dieticians – and is characterised by:

- A high standard of service in the main centres
- A lack of sufficient resources to meet demand
- Variable support for paediatricians and dieticians in district general hospitals
- No guaranteed 24/7 access to specialists
- No guarantee that children aged 12 or over will be referred to paediatric GHN services.

- Many gaps in services.

About 50% of children with, for example, inflammatory bowel disease will be managed by adult specialists, often surgeons not gastroenterologists. Initial investigation is often sigmoidoscopy and studies have shown that this may increase length of time to diagnosis from 12 to 20 weeks. Other problems related to management by adult specialists include:

- Nutrition therapy is less likely to be offered
- Growth and development is less likely to be monitored (growth may be impaired as a consequence of the disease).

Clear guidance exists on how and where children should be treated:

- BSPGHAN – Guide for Purchasers, which informs service commissioners what to look for
- Nutritional standards from NHS QIS and BAPEN, including that all children should have access to nutritional support teams
- The National Service Framework for Children.

This guidance, and the findings of research studies, all agree that children should not be seen in adult service environments.

Capacity is an issue but there has in the past, been no systematic approach to workforce planning and training through out Scotland. This is a UK issue because specialists will move around the four countries, but England and Wales are 10 years ahead of Scotland on this issue. Currently in Scotland, there is a recognised training programme for doctors, nurses and dieticians, however, postgraduate deans are unsupportive of the national training programme. What is required is a national strategy for specialist services.

The main current problems for services are:

- No easy access to services for 50% of children
- PGHN staff are unable to cope with the workload.

Any future service model needs to address these problems as well as provide equity of access for all children outside the main centres. The potential service structure to solve these problems would feature:

- A national PGHN service for Scotland
- Outreach services to cover all of Scotland's children
- A 24/7 telephone advice service for advice from consultants
- Doubling of medical, nursing and dietetic staff; all three staff groups need to be increased together to provide an adequate service.

The pilot study group's optimal configuration of PGHN services in Scotland is to develop:

- The current services in PGHN with proper staffing and resourcing of each of the three regional centres
- Comprehensive services for the whole of Scotland, to support the clinical workload of district general hospitals with the creation of a PGHN Network. Supporting staff in nursing and dietetics is essential to the development of these services
- The provision of expertise for the assessment and care of uncommon, high-intensity medical and surgical problems which require acute and chronic tertiary 24-hour specialist expertise
- A multiprofessional service for children receiving HEN, led by specialists nurses and dieticians.

6.2 PAEDIATRIC NEUROLOGY

SPEAKER: DR ROBERT McWILLIAM, CONSULTANT PAEDIATRICIAN, ROYAL HOSPITAL FOR SICK CHILDREN, GLASGOW

The aims of the paediatric neurology service in Scotland are:

- Together with neurodisability services, to provide accurate diagnosis, appropriate information and effective care to children and their families, enabling them to enjoy the best possible quality of life.
- For as many of these children as possible to become independent, tax-paying and voting adults.

The service cares for children with a wide range of neurological problems, some common some rare, including:

- Epilepsy and paroxysmal disorders
- Learning disability
- Motor disorders
- Neuromuscular disorders
- Acute neurology (including traumatic and non-traumatic injury).

The incidence and prevalence of these problems is:

- Epilepsy: 10/1,000
- Other paroxysmal disorders: 15/1,000
- Cerebral palsy: 2/1,000
- Neuromuscular disorders: 1.5/1,000
- Acute brain injury: 25 /1,000
- Learning disability: 30 /1,000.

The service has a range of facets:

- Emergency/on-call service
- Neuro-intensive care and neonatal neurology
- Neurophysiology (including EEG)
- Diagnostic neurology
- Specialised services (e.g. epilepsy surgery, intrathecal Baclofen, interventional radiology).

Currently, services are generally provided via a system of local and national networks. A uniform standard of service is maintained through meetings, networking and so forth. Established networks which input to standards and provide information include the Scottish Muscle Network and North of Scotland Child Neurology Network. A managed clinical network for epilepsy is being developed.

Scotland has eight consultant paediatric neurologists (one per 500,000, BPNA 1998) but recommendations from 1998 suggest 11 are needed. Consultants currently work 60 hours, although that allowance does not include time for district general hospital networking. In the UK overall, training of paediatric neurologists is on target for the recommended necessary expansion, although Scotland is a net exporter of paediatric neurologists to all parts of the world.

More work is required to establish standards and outcome indicators, for example, for epilepsy (SIGN, NICE), brain injury, and specialist investigations (e.g. what are appropriate waiting times for children).

Education and information is available in a range of media. Some is web-based (e.g. from the Scottish Muscle Network). Some units provide in-house education, although this is mainly for nurses and AHPs. Literature is generally available, for example, from voluntary groups and the

pharmaceutical industry, and paediatric neurology centres also produce their own literature. Parents are involved in planning and running networks (e.g. Scottish Muscle Network and developing epilepsy network) which helps to keep them informed.

Research in this area is collated and promulgated through networks and SIGN. There is a compelling need for audit of current practice and standards (e.g. respiratory management in neurological disorders).

There is not a specialty that does not, at some time, interface with paediatric neurology services. Apart from obviously patients/families, the list includes:

- Neurodisability
- Neurosurgery
- Laboratory services
- Education services
- Nurses and AHPs
- Wheelchair services
- Child psychiatry
- All paediatric medical and surgical specialties
- Adult neurology, disability, respiratory medicine, and orthopaedic services (transitional care).

There are several possible options for service delivery:

- Maintaining the status quo, although taking account of the European Working Time Directive would mean either decreasing output by 33% or increasing capacity by plus 50%
- Continue network development (improved effectiveness but not efficiency)
- Develop outreach (NESCOAN, Dumfries). Outreach provision in Scotland is well behind the situation in England
- Resolve anomalies, for example, if you live in Dumfries you have to travel to Edinburgh for an MRI scan
- Develop nurse and AHP provided services (e.g. epilepsy, cerebral palsy, neuromuscular services)
- Improve collaboration with neurodisability and adult services.

The group recommends the following for existing individual parts of the paediatric neurology service:

- Epilepsy and paroxysmal disorders

Diagnostic and management services are currently provided in Child Development Centres, District General Hospitals and Tertiary Centres with local networks operating in most areas.

Recommendation: Future provision should be via the Scottish Managed Clinical Network

- Diagnostic Neurology

Services are currently provided through local networks linking Child Development Centres, District General Hospitals and Tertiary Centres with national collaboration (diagnostic problem solving) via the SPNG.

Recommendation: No change is suggested

- Learning Disability

Services are currently provided principally through Child Development Centres/District Child Development Services, with diagnostic issues being addressed through the diagnostic neurology process. However, not all children are investigated to the same extent which can mean that many treatable/manageable conditions go are missed.

Recommendation: No change is suggested but it may be helpful to look at specific aspects of learning disability particularly where issues of inequality and inadequacy of service are considered.

- Motor Disorders

Services are currently provided through local networks based in Child Development Centres, District General Hospitals and Tertiary Centres with some specialised services being provided at a national level (intrathecal Baclofen).

Recommendation: No change suggested

- Neuromuscular Disorders

Services are currently provided through local networks in a very similar way to the service for children with motor disorders.

Recommendation: It is suggested that the present arrangement should continue but supported by increasing collaboration and standard setting mediated through the Scottish Muscle Network (note that this is not a Managed Clinical Network in the conventional sense but a web-based forum for communication, accessible to professionals and parents and covering all ages from 'conception to resurrection').

- Acute neurology

Services are currently provided through local networks based at District General Hospitals and Tertiary Centres with considerable flexibility in referral patterns and national collaboration through the SPNG.

Recommendation: No changes.

- Emergency/on-call service

Services are currently regionally based with a managed clinical network evolving in the North East of Scotland. Present consultant numbers do not permit 24 hour 'on site' cover and even the present level of 24 hour telephone cover will not be sustainable when the European Working Time Directive comes into force.

Recommendation: The possibility of a National On-call Service has been raised but needs considerably more discussion.

- Neuro-Intensive Care and Neonatal Neurology

Services are currently provided mainly in Tertiary Centres but Neonatal Neurology input is provided at District General Hospital level with local network support from Tertiary Centres on occasion.

Recommendation: No changes suggested but may be imposed depending on reconfiguration of Neonatal and Paediatric Intensive Care.

- Neurophysiology (including EEG)

There are currently considerable variations in access to and, possibly, the quality of these services. The lack of uniformity in services makes it difficult to share information, equipment and so on.

Recommendation: These services need further discussion. Continuing network development will enhance uniformity and equality of provision.

- Specialised services (Epilepsy Surgery, intrathecal Baclofen, interventional radiology)
- These might be dependent upon changes elsewhere (for example Paediatric Neurosurgery, evolution of Scottish Managed Clinical Network for Paediatric Epilepsy).

Recommendation: Intrathecal Baclofen may well be a service which could be provided at more than one centre once sufficient experience had been gained by the current provider.

The group has also identified elements that are missing from current service provision:

- Designated neurology/neurodisability consultants in each district
- Tertiary outreach to districts
- Adult services to enable transition as children grow older
- Sufficient manpower.

6.3 ONCOLOGY AND HAEMATOLOGY

SPEAKER: DR HAMISH WALLACE, CONSULTANT PAEDIATRIC ONCOLOGIST AND PART-TIME SENIOR LECTURER IN THE DEPARTMENT OF REPRODUCTIVE AND DEVELOPMENTAL SCIENCES, UNIVERSITY OF EDINBURGH

There are around 1,400 new cases of childhood cancer (i.e. in children under 15) in the UK as a whole each year, and between 120-140 cases each year in Scotland. There are around 40 deaths each year in Scotland. The huge success story is the steady increase in five-year survival rates since the 1960s, in some cancers as high as 80%.

Issues which will have an influence on services include:

- The number of staff, in particular the European Working Time Directive. To sustain services, capacity needs to be increased significantly
- Clinical governance, including standards of care, intensity of care, equality of access.

Factors which will influence the patient's journey through services are:

- Presenting symptoms
- Diagnosis (biopsy/excision)
- Staging (imaging)
- Treatment plan (surgery, radiotherapy, chemotherapy)
- Geography (rurality, travel), many patients have to travel great distances for treatment and support
- Supportive care
- Education of the patient/family, preferably at home
- Palliative care, preferably at home.

Care is provided by all members of the multidisciplinary team. Treatment for young children is challenging, for example, chemotherapy lasts for many months, surgery can be extensive and harrowing.

There are 22 UKCCSG centres in the UK. Currently there are three centres providing services in Scotland:

- Glasgow (5 consultants)
- Edinburgh (3 consultants)
- Aberdeen (1 consultant).

It is estimated that 7.2 consultants are required to provide 24/7 care in one centre.

In-patient activity tends to remain relatively constant, at between 40-60 patients at any one time. Day case activity peaks and troughs throughout the year, although since April 2000, the day case workload overall has been steadily increasing. It may be that some of this day case activity can be carried out at home.

Four levels of care are provided:

Level One

- Initial contact
- Diagnostic suspicion
- Palliative/terminal care
- Emergency care

This level of care should be available at every district general hospital with a paediatric unit.

Level Two, which is Level one care plus

- Management of ill/septic child
- Blood product support
- Out-patient chemotherapy

Level Three, which is levels one and two plus

- In-patient chemotherapy
- Intrathecal chemotherapy (high risk procedure)

Level Four (Tertiary), which is levels one, two and three plus

- Diagnosis, staging and management
- Paediatric neuro-oncology
- Bone marrow transplantation
- Phase I/II studies
- Academic
- Training.

Unresolved issues for paediatric oncology services in Scotland are:

- Academic needs of professionals (these are continually increasing and there is a need to be able to train the specialists of the future)
- Dealing with late effects (need to improve SIGN guidelines)
- Teenage and young adolescent children
- Supportive therapies – pathology, radiotherapy, PICU
- Recruitment and retention of medical and nursing staff.

The specialties which support cancer care, and are fundamental to an effective service, are under severe pressure

The group's recommendations are:

- Option appraisal to consider one, two and three centre solutions and examine outcomes
- Formation of managed clinical networks – National paediatric SCAN
- Recognition as a national service

The current configuration is unsustainable in the medium term.

6.4 RESPIRATORY PAEDIATRICS

SPEAKER: DR NEIL GIBSON, CONSULTANT IN RESPIRATORY PAEDIATRIC MEDICINE, ROYAL HOSPITAL FOR SICK CHILDREN, GLASGOW

Tertiary respiratory services for children see a core of difficult to manage patients, that is those with uncommon problems in common disorders (e.g. severe asthma).

Other facets and activities of the service include:

- Caring for children with rare complex disorders, (e.g. interstitial lung disease), and technology-dependent children (e.g. those on home ventilation; technology-dependent children is a group that is presenting an increasing workload and that encompasses social issues)
- Supporting other specialist services (e.g. ITU, oncology, cleft lip and palate). It is important to take account of the 'knock-on' effect of developments in other areas and the need to look after children whose respiratory problems are secondary to another illness and they are looked after by non-respiratory specialists
- Providing a specialist opinion
- Specialist investigation
- Planning and initiating management
- Disease monitoring
- Liaison with secondary paediatrics
- Education and training. In relation to this, it will be important to explore new ways of working, a process which should involve all professions concerned with child health
- Research, audit, guideline development.

Much of the work carried out by the service is new, that is, it did not exist 10 years ago. Some disorders are treated today that were not treated previously, and new factors are leading to new health problems (e.g. obesity in children).

Currently, the service comprises four university teaching centres and some district services where there are highly skilled specialists. But services are patchy and tend to rely on clinician interest and enthusiasm to maintain and develop the service. Lines of communication are unclear. There is a large and increasing demand from other speciality services.

The service does, however, have certain strengths:

- A young consultant work force
- Some good investigative equipment which is shared between areas
- Talented specialist nurses/AHPs
- A strong academic base
- Availability of audit tools
- Scottish Paediatric Respiratory Interest Group (SPRING)
- Backing from patient/parent groups (e.g. the Cystic Fibrosis Trust).

Potential future configurations may feature:

- A few single centre services
- Two units with full sleep and ventilation services, also supporting ITU (probably at either end of the M8)
- Three centres doing bronchoscopy
- Four appropriately staffed units with lung function and basic sleep diagnostics, supporting local secondary care. This would require doubling the workforce and some specialist services could not be sustained over four centres.

Problems facing on-call services include:

- The fact it is a 'hand-on' specialty at consultant level
- The balance between secondary/tertiary patients in larger centres.
- Should there be a national on-call telephone advice service? This would require better links than exist currently. An audit would need to be carried out to establish demand and show how effective the system would be.
- Should patients transfer to the site at which the on-call consultant is based?

Managed clinical networks need to:

- Develop shared protocols/guidelines (SIGN)
- Provide as much care as close as possible to the patient's home
- Develop clear lines of communication and referral
- Agreed outcomes and audit
- Be adequately resourced.

7. MAIN POINTS FROM THE PANEL DISCUSSIONS

- The service is will find further structural upheaval difficult to cope with, therefore it is likely that future service provision will take place within the existing health board structure. This will need a much greater level of collaboration than currently takes place.
- There is a need to ensure service provision at transition points is truly seamless to avoid children and young people missing out on the multidisciplinary care they require. It is too patchy at the moment, with not all services being available in all areas. That means deciding what is the best way to serve the needs of teenagers and young adults and their parents and families, and developing effective partnerships with adult service providers.
- Managed clinical networks are a valuable model but require proper funding to achieve their potential. The National Framework for Service Change will be looking at alternative funding streams. Start up money is available for MCNs but more thought needs to be given as to how they are resourced in the longer term.
- Effectively involving children, young people and parents and families in service development depends on not only listening to what they say, but acting on their ideas. In Wales the Funky Dragon initiative sets up local partnerships to provide a direct link to the Assembly and Children's Commissioner. Representatives should be chosen from as wide a range of sources to ensure everybody has a voice, and it is vital to choose children, parents and families who have experienced care in different centres or areas.
- The ratio of school nurses to children – currently 1:2,500 – needs to be improved. The number of nurse consultants in children's service needs to be dramatically increased from the current level of one.
- How can the potential of specialist nurses be unlocked? They need to have the full support of all other members of the team, although promoting one professional above the others should be avoided. The scarcity of specialist doctors is a good selling point for the nurse consultant role. All such roles need to be properly funded to ensure they are sustainable and can function to the correct level.
- Senior specialists need to be encouraged to remain in the service in some role for as long as possible to help guide less experienced staff as they learn the in the specialty. To achieve this will require an innovative and attractive package of measures.
- How can telemedicine be used more effectively to overcome some of the problems service providers in Scotland face? It is potentially a very useful tool for practitioners and patients and their families but the technical set up at either end of the link needs to be handled and maintained correctly to ensure it works properly. This means training and employing appropriately skilled people, as well as training doctors, nurses, AHPs and other staff in using the technology. May also be used for education purposes. Technology has the potential to help to keep service provision as close to patients' homes as possible.
- The future configuration of specialist services will need to be considered in relation to the workforce and other service pressures identified during this review.

8. WORKSHOPS

8.1 REDESIGN TO DELIVER (INCLUDING SOLUTIONS)

DISCUSSION

There is a wide range of policies, strategies and other factors which may influence service redesign. These include:

- The National Review
- New deal for junior doctors' hours
- Working Time Directive
- Modernising Medical Careers
- Demographic trends
- Political and public expectations
- Managed clinical networks
- Difficulties engaging with disadvantaged communities
- Regional versus national planning
- Reconfiguration of maternity services
- Reconfiguration of district general hospital services
- Waiting time pressures
- Clinical governance
- Changing professional roles
- Recruitment and retention problems.

Participants were asked to consider several key questions:

- What are the main redesign issues?
- What do you want to achieve by service redesign?
- What do you need to change to improve services for children?
- What are the barriers to change?
- How will we know that redesign has improved services for children?
- How will redesigned services be rolled out nationally?

A cycle of action presents an effective way forward:

- Plan – who, when, why? – data collection
- Do – how? – analyse
- Study – collate and compare – evaluation
- Action – start again and plan next cycle of change.

Examples of redesigned services which have been effective include:

- Mayo Clinic – this involved patients being freed to take their own medication in hospital. It was seen as risky so began with one person on one day working with the medical director. The process was reviewed and improvements made, before the method was rolled out progressively. The project proved successful – it is good for patients and saves money.

- The above method has been replicated in other areas. For example, in Tayside, flexible access to GPs was tried out. It began with one GP whose diary was cleared for one day and appointments booked across the day. After the trial improvements were made, including telephone consultation with patients. The system was continually improved and has also proved successful.

- Audiology services in Tayside were redesigned following analysis of the patient's journey. An 'access clinic' was established which allowed patients to be referred to the service more quickly. This provided a better service for patients and helped reduce the number of wasted appointments.

- Managed clinical networks have the potential to create opportunities for radical redesign of service provision, including how money and other resources are used. But to grasp the opportunity will require providers to start with a ‘blank sheet of paper’, to consider not just medical/health issues, but also, for example, access to services, housing etc. This requires a partnership approach, involving a wide range of organisations and agencies (e.g. in child protection – local authorities, police forces, health boards among others).

One of the problems which complicates service redesign is cost – at a local level, only a small number of children will use tertiary services, so it may be necessary to consider planning at national level. In fact, national planning will be vital in relation to certain aspects of planning. One suggestion was to facilitate this process by creating a Scottish Health Board for Children.

This may cause conflict at local level, depending on how individual health boards envisage services will be configured and how they balance local priorities and resources. So two tiers of planning – regional and national – may be required, without losing sight of local needs.

Services may be duplicated, for example, in areas in different health boards that are close to each other. Some specialist services experience problems due to duplication. For example, rolling out audiology screening of new-born children to many centres could lead to the specialists not seeing sufficient numbers of babies to maintain their skill level. It may not be possible to sustain the delivery of specialist services at multiple sites. For example, it is not possible for every maternity unit to run neonatal ICU services, although this may not be popular patients, the public or staff.

What is needed is a clear, credible agreement on what may be planned at each level – national, regional and local – and agreed process for mapping service need at each level and making decisions on what will be delivered and where.

Communication between specialist teams around Scotland already takes place about how services may be delivered, however problems tend to arise when attempting to implement service changes at a regional level. It may be unrealistic to expect significant investment in training and staff to effect a major redesign of services. The appointment of a national commissioner is potentially the key to change.

Managing public expectation of what services can be provided, in which areas, and what they can deliver, is also important, as is, conversely, patient and public involvement in service design. Attempts to involve the public have had mixed success – some areas have found it difficult to engage the public, while in others, the response has been very good. Much more work needs to be done on this subject, to help people understand what is currently available, what is possible and the problems services face, as well as that their opinions and potential solutions are valued.

Setting and publishing a staged plan with realistic timescales, including ‘quick wins’ and medium term goals, may help to promote public involvement. The experience in England with the National Service Framework for Children shows that you also need to explain how change you will turn an aspirational strategy into an achievable action plan.

QUESTIONS FROM WORKSHOP

- Q1. Where is the national children’s implementation body to drive any plan to completion?
- Q2. How can we engage the public and balance public perception with reality?
- Q3. How can we balance local, regional and national policies?

8.2 PATIENT'S JOURNEY

DISCUSSION

How best can we offer specialist services to all children and provide appropriate care of a high quality? The child must be at the centre of any service and this requires greater patient and public involvement in tertiary service reviews. Some families face financial hardship because they have to attend for treatment at tertiary centres not in their local area.

For many children, their journey as a patient is very complex. The focus should be on what is important to the child, not just what clinicians see as a priority. Communication is key: children and families need to know what is happening to them. The aim should be to provide the best possible care locally and, if that is not possible, to provide adequate accommodation and support for families (including siblings) at tertiary centres.

Clinicians need to establish what information and support families need and co-ordinate communication between different services to the same family. Perhaps a lead worker – one professional the family always has access to – would help this process. In addition, one key person in the tertiary centre could liaise with the child and family's local service providers. GPs need to be more involved in liaison about children being treated in tertiary services. Perhaps a lead GP with an interest in paediatrics could be identified in each area to attend case conferences. This would enable more effective information sharing; a letter for the GP on discharge is not sufficient.

Tertiary centres tend to be 'inward looking'; they should be more open and see themselves as service providers. All Scottish tertiary centres are also secondary care providers.

Key workers (e.g. a health visitor, social worker, counsellor) could be allocated to each paediatric patient for the duration of their hospital stay, to fulfil a liaison (not to make treatment decisions) function for the child and his or her family. The key worker would not need to be a health professional and families may want to identify their own key worker at the beginning or ask for a change at any time in the duration of the stay.

Planning is another key issue. All aspects of the patient's journey (e.g. discharge planning) can be considered on admission. A framework for care, including minimum standards of care, the child's basic needs and important contact numbers, could be developed jointly between children, parents and clinicians. Perhaps each centre could provide an information leaflet, drawn up in conjunction with children, parents and families, or even a 'support pathway', which would include details of the potential sources of support families want to access (e.g. social workers, voluntary services), as well as information about what is available.

Examples of good practice in information sharing include community nurses in Lanarkshire who provide list of contact number for different problems, and the Diabnet system (diabetes specific) which may be adapted for other conditions.

It may be possible to establish a secure website on which all tertiary service providers could post information. Families could be allowed access to the site. It could be interactive with the facility for parents and professionals to post questions and answers.

Such networks for information sharing may require specialist nurses and social workers to be involved.

QUESTIONS FROM WORKSHOP

Q1. Will adequate consideration be given to the needs of families forced to travel and stay with their child in tertiary centres far from home?

For example, the need for

- accommodation for parents and siblings
- employees to accept parental absence from work
- cost of travel and the need for car parking.

Q2. Will specialist and secondary (local) paediatric teams include a family support/care co-ordinator in addition to clinicians?

Q3. Will information technology (IT) developments be adequate to ensure timely, relevant sharing of clinical information between tertiary centres and the local district general hospital (DGH) and primary care teams?

CONTENT OF WORKSHOP FACILITATOR'S SLIDES

Patient's journey: Oncology scenario

Girl, aged 9 years

- Headache for 9 months
- Vomiting for 2 weeks
- Unsteady gait for 1 week
- Local hospital
 - MRI scan
 - Diagnosis of posterior fossa tumour
 - Paediatric neurology/oncology/neurology discussion

Referral to tertiary oncology centre

- Surgical removal of tumour
 - Performed in tertiary centre
 - Required PICU following surgery
- Craniospinal radiotherapy arranged
 - Delivered in tertiary centre Monday-Friday (weekends at home)
 - Supportive care delivered by local hospital
- Chemotherapy
 - Delivered in tertiary centre
 - Supportive care delivered by local hospital

Other issues which have an impact on the management of this child and family

- Single mother who is breadwinner and has health problems
 - Financial issues
 - Support
- Twin brother developed schooling problems and behavioural difficulties
 - Psychology referral

Ongoing problems for child

- Frequent admissions to hospital
- Eating problems for patient
 - Nasogastric feeding

- Schooling issues for patient
 - Body image
 - General malaise; home schooling organised

Long-term issues

- Recurrence of disease – 35%
 - Palliative
 - Terminal
- Long-term effects of treatment
 - Hypopituitarism
 - Second tumours
 - Growth
 - Intellectual problems

8.3 WORKFORCE, SUCCESSION PLANNING, RECRUITMENT

DISCUSSION

The major issues in relation to the tertiary paediatric workforce are recruitment and training. Inter-professional training is already being developed for allied health professionals (AHPs), but to fit that into the existing curriculum, something else has to be dropped.

One model would be to have a generalist degree followed by an accelerated graduate course because completing a generalist course may help professionals make an informed decision about which speciality to progress to. Specialist training could also include generalist core modules.

The reasons for attrition from medical and other healthcare programmes need to be addressed, as well as why more graduates do not go into medicine. Ways of attracting more people into tertiary services include:

- Creating a better work-life balance – this is crucial to recruiting and retaining professionals
- Valuing paediatric specialist services and practitioners more to engage professionals' commitment – this would include sustained investment in services and research
- Providing more administrative support to allow clinicians of all professions to spend more time on care and treatment, and more time supervising trainees – this involves getting the basics right, providing office and IT infrastructure and systems that can talk to each other. This would save time and money, encourage effective networking (passing on good practice) and information sharing, and provide access to distance learning
- Create teams with the correct mix of skills so that each professional is using his or her skills appropriately.

Revalidation is an important process but professionals need to be granted the time to go through it. What is required is more robust monitoring of continuing professional development activity and more objective assessment methods. In medicine the 'built-in' study budget is welcome but insufficient; for example, it does not relate to the cost of courses or attending conferences. Other disciplines do not even have access to any study funds. A greater number of multidisciplinary training courses should be made available in Scotland to keep costs down.

So, it will be important, in developing the workforce, to:

- Value and promote multidisciplinary skill mix, expanding roles and boundaries
- Develop creative and child/family-friendly ways of working – creative thinking and flexibility is needed to explore a wide range of options
- Get the basics right – including infrastructure; well maintained, appropriately sized accommodation; IT systems; administrative support; and the overall environment (e.g. healthy food choices available on-site for all)
- Increase training budgets, and provide cheaper, multidisciplinary courses (in Scotland) and time to study – for all
- Address reasons for the 'brain drain' – from medical school and other programmes before qualification; away from medicine and other health professions after qualification; and away from Scotland.

Other important points in relation to workforce development:

- Scotland will not have significantly higher numbers of doctors by 2010
- We need to make best use of doctors' and other health professionals' time
- Reform the referrals system to reduce the number of inappropriate referrals
- GPs will require greater support when managing patients of tertiary services in the community
- GP training in paediatrics should be expanded

- Return outpatient appointments may be managed by community based services in the patient's local area
- Community nursing services need to be developed further
- Neonatal paediatric services need to be redefined
- 'Pump-priming' of services is only a short-term solution – services need longer term funding
- Consultant posts may be shared between tertiary centres and district general hospitals – this would help to emphasise integration and raise the profile of services in local areas
- One properly funded and sustainable tertiary centre for Scotland should be considered
- Major structural changes in service delivery need to be planned to take place over longer periods of time (six years is not sufficient time for major change)
- Service users' expectations about what can and cannot be delivered need to be managed as changes are made
- Different solutions and approaches to out of hours cover should be investigated
- Training and supervision issues need to be addressed – for example, consultants must have time to train junior staff.

QUESTIONS FROM WORKSHOP

Q1. How many tertiary centres will there be in Scotland? In particular, how and when will the 'toing-and-froing' between Yorkhill in Glasgow and the Royal Hospital for Sick Children in Edinburgh be resolved? Will we have two centres with overlapping responsibilities (i.e. a 'virtual centre'); or one of the existing centres; or a 'new-build' in Stirling?

Q2. Given that, at present, we are moving towards a 40-hour (European Directive) medical week, where will the 'extra staff' come from to fill the gaps left? How will they be trained? How much will they be paid? Will they be adequately 'mentored' by the doctors in that specialty?

Q3. What happens next? Will this day have been well spent? What mechanism is there to take this debate forward with genuine dialogue between politicians, nurses, doctors, other health professionals and managers?

NOTES RE QUESTIONS

Q1. Crucially important for staff confidence – stability, retention, recruitment ("People's lives") as well as the confidence of the population whose health is the issue! Neonates and TYAs (Teenage and Young Adults) have a special interest in this question.

Q2. If this develops into a Hospital at Night initiative, nurses alone cannot be expected to take the greatly increased responsibility. Perhaps a 'new' kind of senior nurse is needed, Scottish brand!

Q3. We need more information to all registrants for today and a TIMETABLE. We also need more 'working group' discussions en route to the final solution.

CONTENT OF WORKSHOP FACILITATOR'S SLIDES

Welcome to 2010 ...

Our NHS ...

- Consultants work only 40 hours per week
- Care is multiprofessional and team based
- Nurses have defined 'caseloads'
- Nurse consultants, advanced practitioners and assistant practitioners provide core service

- ‘New’ professions – medical support staff
- HCAs – technical and monitoring roles
- Workforce reflects changed pattern of clinical activity
- Workforce is predominantly female
- Junior doctors are supernumerary and training is competency based
- Medical training is generalist (and shorter), followed by specialisation
- Multiprofessional entry to all healthcare professional education has reversed recruitment issues
- Protected entry into healthcare educational programmes from remote areas to reverse depopulation
- Learning is multiprofessional and core in all roles and supported by information management and technology
- All professions are regularly revalidated
- Integrated/collaborative approach through all levels of care – primary/secondary/tertiary
- Out-of-hours provision is limited
- No waiting lists

Your task ... you have 40 minutes in groups of no more than five people to answer, ‘So how did we get there?’

8.4 LESSONS FROM THE TERTIARY REVIEWS

DISCUSSION

Key questions and points from the workshop

- Do we want a key specialist or nurse specialist to see children?

Participants discussed the presentations on the pilot reviews in general. There was no real sense of what children/families feel about this and what they want.

- Clarity is needed around what happens next. What resources will be allocated?

There is a need to define how 7/24 cover for tertiary services is provided. Where does cystic fibrosis fit in within the groups? Resources and workforce have to have a balance for population. Perhaps Scotland could be treated as a big health board area, although there may be problems relating to problems around ITU provision. Networking is very useful. Problems existing relating to ensuring how each link into secondary care and support for specialists.

- What do children and families think?

The respiratory pilot groups received feedback/input from families of children with cystic fibrosis. They want care not that far from home and clear links with a specialist centre. Participants felt that a definition of tertiary/specialist is needed.

In relation to oncology and haematology, there is no data about what families want. The voluntary sector helps with a lot of the care provided. Families want best care and the best specialists in easy reach; best quality will always be chosen over where the care is provided. Rural families will travel to get the best quality care.

- Should Scotland be following the Wales model, or Great Ormond Street example?

Participants discussed how different services evolve differently in the four countries of the UK. A definition (i.e. age limit) of a child is needed. There are also questions about how to deliver transitional care after the cut off 18 years. A national plan followed by commissioning is one potential approach. What Paediatric care should look like needs to be decided and then implemented properly. The interdependent nature of tertiary paediatric services was seen as a strength, but the relationship with secondary care needs to be improved.

- Managed Clinical Networks

NICE guidelines set the age limit for access to tertiary paediatric services at nearer 21/22 years. How MCNs might fit with the Wales and Great Ormond Street examples, was also discussed.

- What do people think of the different models? How should networks be set up? What are the boundaries?

The Cleft Lip & Palate Network defines care clearly. The network is condition specific and includes tertiary and secondary care. A commissioning network is perhaps needed. Networks can be run once it is clear what they are trying to deliver. Are MCNs sustainable at tertiary level. Problems exist including, workforce numbers/gaps in the system/the influence of the type of service.

Participants wondered what the reaction would be to cutting down the number of specialist sites and rationalisation? Reductions in specialist centres would need to be accompanied by improvements in and expansion of outreach services. The ideal model may be co-location on one site, but participants wondered where this might be. A clear definition of what is wanted would be needed, and decisions taken about what would need to be on-site and what would not. Participants agreed that it would depend on what type/level of service is required.

- European Working Time Directive

Participants emphasised that that this is an opportunity to put forward ideas for tertiary and paediatric care.

- Bristol Kennedy Report – do participants go along with the findings?

Not every type of care has to be delivered at a tertiary centre. Tensions exist between tertiary and secondary centres.

- Patient's journey

Improved access routes to services are needed. Not every child needs high level care; some form of filtering process is needed. But participants wondered how this would be controlled. Care pathways partly achieve this function but participants agreed that greater clarity is needed.

- Recruitment

The workforce in each group must be sustained once the appropriate numbers have been reached. Some participants mentioned the Birmingham/Leeds model. A choice needs to be made as services are not sustainable. The problem is not just money – the fact is that there are not enough people. If a single centre approach is adopted then a clear message needs to be communicated to children, parents and families. Participants discussed which different services could be delivered in different areas. It was emphasised that what was discussed at the conference will be fed into the national framework, which does have a short timescale. Hard decisions need to be made to plan effectively for the next 20 years. Do we have genuine powers and consensus? A workforce model is required proposing numbers/options/consultation.

QUESTIONS FROM WORKSHOP

Q1. How will all staff – not just doctors and nurses who seem to be the focus of the conference – be made aware of the outcomes from the conference? How will they be able to contribute to the overall process?

Q2. Will Scotland have an equivalent of the NSF? It seems to be having a significant impact both in England and Wales, with recommendations informing good practice.

8.5 DEVELOPING THE ROLE OF HEALTHCARE PROFESSIONALS

DISCUSSION

A national overview of new role development for all professions is needed. Many professionals are feeling frustrated that funding for new roles is more often than not only for the short term. Many are also frustrated that they are competing for funding with other services which deal with one of the national priorities.

What is required to facilitate role development is:

- A national overview of new role development for all professions, to ensure that: services are not duplicated unnecessarily and that levels of existing need are met properly; that professionals working in new roles are properly managed, supervised and supported, with an integrated career and competency pathway; and that time and money is not wasted on frequent (unsuccessful) applications for funding
- Targeted, sustained funding for new children's and young people's services so that services can be developed maintained in the long term (including money to cover holidays and sickness absence), to meet need and raised patient and public expectations
- A systematic approach to dealing with the high vacancy rate in specialist services before they are extended further, which would increase demand
- Support from medical colleagues for the development of new roles, not just in nursing, but also in, for example, the allied health professions
- A clear legislative framework so that professionals are certain about what is and is not possible (e.g. parameters of nurse prescribing)
- A clear framework for accountability; for example, is a nurse working in a new role an independent practitioner or responsible to a medical director? This would also entail ensuring those with responsibility have time to exercise it.
- A review of the large number of 'one consultant' tertiary services, which may not be sustainable
- A clear, comprehensive system for service planning, to take account of and reconcile local, regional and national priorities and needs
- Effective workforce planning based on the baseline workforce data (Scottish Health Workforce Plan 2004 Baseline), including planning the skill mix required for different teams in different specialties (who do we need in the whole team to serve the population)
- Greater collaboration between services and different health board areas to facilitate recognition of problems and potential solutions
- Increased use of available technology to encourage networking, communication and the sharing of best practice
- Proper funding of continuing professional development activity, taking into account issues such as backfilling posts while staff are studying or attending a conference
- A systematic approach to succession planning

A 'whole Scotland' children's service was suggested, separate from adult services with its own finance and organisational structure, including services for healthy children.

QUESTIONS FROM WORKSHOP

Q1. How is the Scottish Executive intending to involve paediatric practitioners in the development of service models to meet the needs of children and young people?

Q2. How is the Scottish Executive going to support the development of extended roles for allied health professionals and nurses to support the development of children's services on a long-term basis?

Q3. How is the Scottish Executive going to promote the role of the expanded healthcare team to children, young people and their families and carers?

CONTENT OF WORKSHOP FACILITATOR'S SLIDES

Modernisation Agenda

- New Pattern of Service delivery
 - Emergency departments
 - Networks of care
 - Location of services
 - Night cover
 - Outreach
 - Improve patient safety
 - Improve access
 - Increasing community focus
- Service redesign and delivery
 - Process mapping
 - Gather the data
 - Improve the patient flow
 - Smooth variation in admissions process
 - Reduce unnecessary handoffs
 - Systems of handover
 - Managing evenings
- New technologies
 - Point of care testing
 - Mobile phones
 - Better use of current technologies
 - e.g. bleeps, x-ray
 - Electronic patient records
 - Video technology
 - Decision support systems
 - Increasing complex needs
 - Increasing technology at home
- New ways of thinking
 - Better working hours
 - Extended roles
 - New roles
 - Team working
 - Nurses/physiotherapists/technicians/
pharmacists
 - New ways of learning
 - Protocol-based care
 - Integrated care pathways

Education and training – for roles

- Blurring boundaries
 - Core skills and competencies [knowledge]
 - Shared and multiprofessional learning at pre and post-qualification levels
- Children and young person's perspective: seen by the right person with the right skills and competencies

The legal framework – roles

- Legal standards
 - Constitutional standard – the 'rule of law'
 - Minimum quality standard – the 'rule of negligence'
- How do these apply to, for example:
 - Ordering diagnostic investigations such as pathology tests and x-rays
 - Prescribing medicines and treatments, supplementary prescribing and extended formulary, and Patient Group Directions
- Issues
 - Legal boundaries
 - Sufficient training, education and preparation

The professional framework for roles

- Professional codes of practice, for example, Code of Professional Practice (Nursing and Midwifery Council)

- Clinical governance – the provision of high quality patient care entails treating the patient as a whole

- Issues

- Professional indemnity insurance
- Employer's liability
- Individual responsibility and accountability

Are these true or false?

- Patient determines the need for care

- 'Treatment starts at the hospital door'
- 'Ambulance staff have to take patients to the hospital'

- Initial assessment and treatment

- 'Nurses and AHPs can only see and treat patients with minor illness and injury'
- 'Patients cannot be discharged following initial assessment and advice by nurses and AHPs'

- Investigations

- 'Nurses and AHPs are not allowed to refer patients for tests and investigations'
- 'Nurses and AHPs are not allowed to interpret test results'

- Further assessment and treatment initiated before referral to specialist team or treatment completed

- 'Nurses and AHPs are not able to make an initial diagnosis without referring the patient for a medical opinion'
- 'Nurses and AHPs are not able to initiate or complete treatment based on their clinical assessment of the patient'
- 'Nurses and AHPs are not able to supply or administer medications without a prescription from a doctor'
- 'Nurses and AHPs are not able to prescribe medications'
- 'Nurses and AHPs are not able to develop an initial clinical management plan or complete certain treatments'

- Patient transfer or admission

- 'Nurses and AHPs are not allowed to refer patients for a specialist opinion, for example, referral to surgeon, physician or other nurses or AHPs with specialist knowledge and skills'
- 'Nurses and AHPs are not allowed to transfer patient care to primary care team, intermediate care team, or social care'
- 'Nurses and AHPs are not allowed to transfer patient or admit patients to an acute hospital bed including medical assessment unit, clinical decision unit, observation beds, acute medical or surgical beds'

- Discharge

- 'Nurses and AHPs are not allowed to make a decision to discharge patients from hospital or transfer care to primary and community teams, when they are medically fit to be discharged'
- 'Nurses and pharmacists cannot transcribe TTOs or write discharge letters'

Succeed or fail?

- The success of new roles depends on their fit within:

- The wider health team
- How individuals are educated, supported and supervised
- Effective methods of communication

- Participative decision making
- Leadership
- Authority
- Channels of clear accountability

Discussion points

- What happens at the moment?
- What be a good outcome?
- What needs to happen to achieve this?
- Who needs to be involved?
- How would the solutions differ in a different setting?

9. CLOSING REMARKS

SPEAKER: MALCOLM WRIGHT, CHAIR, CHILD HEALTH SUPPORT GROUP

This event could mark a turning point for tertiary paediatric services in Scotland. The organisers recognised the problem at national level and the real need for decisions to be taken and changes to be planned.

The policy and strategy context is in place to drive forward developments quickly to plan changes to meet the needs of the target population.

The core issues are:

- Equity of access to services
- The 'critical mass' of patients to sustain services which are not working in isolation
- Medical advances which mean more conditions are treatable and more patients are surviving serious illness longer
- The effects of societal and health trends
- The development of new roles and new ways of working
- The need to strike the correct balance between what is planned at national, regional and local level
- Workforce challenges, such as how the required growth in staff numbers is funded and where the people to fill the roles and posts are going to come from
- Resources to sustain the type of service that is needed, given the other pressures (e.g. pay reforms) on budgets. It will be important to make the best use of resources by doing things differently and more efficiently. There is a need for radical change in some areas, but this must be planned properly.

The information gathered at the conference provides a strong base for the next stage of the process and some momentum to take it forward, but we need to establish mechanisms for making decisions.