SUMMARY OF DISCUSSION: SPECIALIST PAEDIATRIC SERVICES SUB GROUP MEETING

1000 HRS MONDAY 16 AUGUST 2004
Scottish Executive Offices, Victoria Quay, Edinburgh

Present:

Peter Bates (Chair), Chair NHS Tayside
Myra Duncan Advisor National Planning Team
Lorraine Currie Child Health Commissioner, NHS Grampian
Jackie Sansbury Regional Planning Director, South East and Tayside Regional Planning Group
George Youngson, Professor of Paediatric Surgery, NHS Grampian
Isabel McCallum Director of Nursing, NHS Lothian University Hospitals Division
Robert Stevenson Child Health Support Group Co-ordinator, SEHD Women’s & Children’s Unit
Zoe Dunhill Clinical Director Children’s Services, NHS Lothian University Hospitals Division
Callum Kerr General Manager West Central Division, Scottish Ambulance Service
Andrew Dunlop GP, Cramond Medical Practice, Edinburgh
Gwen Garner Action for Sick Children
George Farmer Consultant Paediatrician, NHS Highland
Morgan Jamieson Medical Director Yorkhill Hospital, NHS Greater Glasgow
Deirdre Evans, Director, National Services Division
Margaret McGuire Nursing Officer, SEHD

Apologies:

Stewart Forsyth Clinical Director of Paediatrics, NHS Tayside

Meeting

The group met for the first time to discuss the following issues:

- Background to the development of a National Framework for Service Change in the NHS in Scotland
- Agreement of the Specialist Paediatric Services Commissioning Document
- Setting the Scene
- Next Steps and Information Requirements

1 Welcome

Peter introduced himself and invited introductions from around the table. He conveyed the Minister’s and the Chair of the Advisory Group’s appreciation for colleagues’ acceptance of the invitation to participate in this work. There was full representation from invited members except Stewart Forsyth who is currently on holiday, but had accepted the invitation to join the group.
2 National Framework for Service Change in the NHS in Scotland

Peter explained that he had been asked to chair this sub group as a member of the National Advisory Group and he expressed the importance of involving and taking advice from clinicians. He acknowledged the amount of work that had been done to date and stressed that this group would not go over old ground but focus on securing clarity on decision making for Ministers.

Peter explained the background to the development of the National Advisory Group and the expectation that the National Framework will ensure clarity over the decisions that Scotland needs to take for its health services over the next 15/120 years, taking the clinical and wider community through this process of decision making and understanding the reasons for change.

Highly specialised care was one element of the work of the Group and specialist paediatric services along with neurosciences had been identified as specific areas for focus. He emphasized that this group could bring together previous work, achieve a consensus of clinical support and set out what is needed for specialist paediatric services for Scotland.

Discussion points:

The issue was raised of where previous work had not been taken forward, it had not achieved consensus and therefore decisions were not made. It was important to support decision making by achieving clinical consensus and clarity on what needs to be done.

The Terms of Reference of the National Advisory Group were noted.

3 Expert Advisor

Peter informed the group that he had considered it helpful to him as a lay chair to secure expert advice as support to him in this role. The President of the Scottish Committee of the RCPCH had been approached and Dr Anna Murphy has volunteered to act in this capacity. He explained that this did not cut across the work of the group, which needs to take a strategic view.

Discussion points:

There is an option to get advice from the Academy of Colleges and Faculties in Scotland for the overarching framework for highly specialised care.

There was discussion about the need to agree an upper age limit when considering services for children particularly for planning. This varies across Scotland from the ages of 12 to 15, but is generally around 13. The considerations were identified as:

- The transition years are currently not managed adequately for children and adolescents. It would be helpful to define responsibility for transitional care
- The current practice in Scotland is such that were there are complex needs children tend to be admitted into the paediatric sector and straightforward treatments to adult services.
A change (increase) in the age ceiling would impact as a volume increase in activity for which there is currently no capacity.

There would be some clinical issues, however the main considerations are the appropriateness of the ambience, style of delivery and the management of choice in children at different stages of maturity.

There is inconsistency between hospitals and hospital is only one element.

There would be benefits in medicine mirroring education.

There is a divergence of clinical opinion.

The National Service Framework for Children in England is using the Kennedy recommendations concerning purpose built accommodation for up to 16 year olds.

There is a need to consider adolescent medicine.

In specialised services eg cystic fibrosis, the needs are different depending on age and although the skills may be in a paediatric hospital the setting may not be appropriate.

Child protection issues for children receiving care in an adult setting.

Action:

It was agreed that development of a policy framework would be beneficial. Myra will write up the points that have been made and draw together recommendations as a start point for consideration.

4 Setting the Scene

Myra acknowledged the significant amount of work that has been done previously and the work of the Paediatric Specialist Services Sub Group of the CHSG. There was a wealth of literature and examples of models of care which this group could draw on. She set out a number of key issues facing paediatric specialist services:

- Unsustainable in their current form, some immediate priorities around paediatric oncology/haematology and PICU
- Inconsistency in referral, access and care across Scotland
- Demand and supply issues currently and for the future
- Demographic trends – volume of activity and labour market
- Nature of the service
- Needs of children
- Interrelationships with other services
- Integration across sectors

(speakers notes attached as an appendix)

George Youngson explained the status of the work of the Paediatric Specialist Services Sub Group of the Child Health Support Group. The pilot areas had reported and recommended a range of approaches for the future for their service areas including network, regional and national approaches. Some issues identified:

- Absence of volume:outcome information to guide considerations
- Regional vs national approaches
- Inconsistency in patterns of referral and zoning with planning
- Interdependencies of specialties in terms of sustainability
It was confirmed that previous work will not be duplicated, this group has the opportunity to set out what needs to be provided at a Scotland wide level and how it is provided.

**Discussion points:**

There is a need to take account of the EGAMS work.

Zoe highlighted the importance of the integration of a specialist centre with local services. In a remote setting the link for the child and its family tends to be a nurse or AHP, therefore this group needs to take cognisance of the importance of investment in community services as complementary to local paediatric care and specialist services.

**Action:**

Zoe agreed to set out the issues and put forward recommendations for discussion at the next meeting.

**Discussion points:**

Morgan described a model of a single service with levels:

- 3 children’s hospitals providing local care and infrastructure for paediatric services
- individual services and how they work with the local care arrangements which may result in a change in ways of working or locations
- tertiary services being planned and managed on a cohesive basis for Scotland

There is recognition that there has been substantial strategic drift in children’s services in Scotland and that there is a need to consider what will be needed in 2021:

- The workforce will be different as well as the care being provided
- There is a need to look at things nationally to maintain skills, the low numbers of children make it difficult to do this over a number of centres
- Decisions regarding investment, capital, training need to be informed
- At the 11 June conference the Minister identified the need to coalesce and set out an action framework
- There are issues about critical mass for specialist services at local level
- Need to make Scotland attractive to recruit and retain staff

This group should draw these issues together and set out a framework for decision making to establish a durable structure for children’s services in Scotland for the future.

5 **Commissioning Document**

Myra explained that the commissioning document was generic for the highly specialised care workstream and could be tailored. It was agreed.

**Discussion points:**
Due to the amount of work already completed, discussion should be focussed on identifying and agreeing what decisions need to be made.

The issue of PIC was agreed as an area which might be looked at. Information on activity trends and projections for the future should be considered. PIC’s relationship with other services is integral to their sustainability.

6 Next Steps and Information Requirements

Actions:

A number of pieces of work were identified for the next meeting:

- Drawing together the issues regarding changing the age ceiling - Myra
- Summary of information available and what the gaps are – Myra
- Provide information on current national services - Deirdre
- Interim position on where the Paediatric Specialist Services Review is and the issues for decision making – George Youngson
- The relationship between local and specialist care and associated issues – Zoe
- Summary of all other current SE work on children’s services – Margaret/Robert

Deirdre circulated copies of the current annual NSD report.

Myra will circulate the following to the group:

- list of information sources – group members should advise Myra of any additional reports or information sources
- report of the parliamentary debate on Argyll & Clyde service changes
- Auditor General’s report on the performance of the NHS in Scotland

It was agreed that the group would use the English definitions of Specialised services for the scope of its work. This information will be brought to the next meeting.

7 Any Other Competent Business

It was agreed that the group should include representation from Allied Health Professionals and Public Health.

8 Date of Next Meeting

Agreed as Thursday 23 September 2004 1000 am in Perth.

It was agreed that Myra would identify a further series of dates and e-mail them to the group.