



BETTER HEALTH, BETTER CARE

National Delivery Plan for Children and Young People's Specialist Services in Scotland

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Acknowledgements

We would like to thank the National Steering Group for Specialist Children's Services and the Children and Young People's Health Support Group, both chaired by Malcolm Wright, for leading and overseeing the work that has resulted in this National Delivery Plan.

We are also indebted to the many staff who contributed to this work and to the children, young people and their families whose views have been a vital element in developing our proposals.

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ISBN: 978-0-7559-5879-5

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Produced for the Scottish Government by RR Donnelley B57674 01/09

Published by the Scottish Government, January 2009

Further copies are available from
Blackwell's Bookshop
53 South Bridge
Edinburgh
EH1 1YS

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Foreword



When the *National Delivery Plan for Children and Young People's Specialist Services in Scotland* was launched for consultation in March 2008 it met a key milestone in our commitments set out in *Better Health, Better Care. The Best Possible Start* section, of that document, clearly indicated that improving the care of some of our most vulnerable children and young people in Scotland is a key priority for this Scottish Government.

The commitment of an additional £32 million over the next three years will ensure the future sustainability of the existing children's hospitals in Aberdeen, Dundee, Edinburgh and Glasgow. It will also allow us to plan for the development of two new children's hospitals in Edinburgh and Glasgow which will mean that Scotland will have the most modern hospital facilities for children and young people in Europe.

However, this document is not just about hospital provision, it is about improving the care of children and young people through a network of services working together. We aim to do this by investing in services throughout Scotland and by supporting the development of care in District General Hospitals and in the community.

The views of children and young people and their families have been the focus of our approach, with the delivery of age appropriate care a key message from the consultation process. I will expect the Implementation Group, NHS Boards and Regional Planning Groups to continue to include these important stakeholders as the *National Delivery Plan* is taken forward.

A handwritten signature in black ink that reads "Nicola Sturgeon".

Nicola Sturgeon, MSP

Deputy First Minister and Cabinet Secretary for Health and Wellbeing

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1 Drivers and Challenges

NATIONAL DELIVERY PLAN – DRIVERS AND CHALLENGES

1. There are over a million children and young people under 18 years of age in Scotland. They make up a fifth (20.4%) of the total population of 5.14 million. Although the numbers of children had fallen over the past few decades as a result of a falling birth rate this trend has changed markedly in the more recent past. The General Fertility Rate has risen by 14% in the last 5 years and the number of births per annum (57,781 in 2007) is now at the highest level since 1998-1999.
2. The UN Convention on the Rights of the Child Article 24 recognises the responsibility to ensure that children enjoy;

“the highest attainable standard of health”

and have access to

“facilities for the treatment of illness and rehabilitation of health”.

3. One of the most significant changes in health care over the last 50 years, reinforced very explicitly by the outcome of the Bristol Inquiry in 2001, has been the growing acknowledgement that children are not “small adults”. In addition to being physically, mentally and socially distinct from their adult counterparts, the illnesses and conditions which they experience and the ways in which these affect them are significantly, and sometimes absolutely, different.

“It seems so obvious it hardly needs to be said; just as children differ from adults in terms of their physiological, psychological, intellectual and emotional development so they differ in their health care needs.”

Professor Ian Kennedy,
Report of the Public Inquiry into Children’s Heart Surgery at the Bristol Royal Infirmary (2001)

4. Childhood is also a time of rapid development – the differences between the newborn baby and the rapidly maturing teenager are more fundamental and substantial than the differences that emerge across the subsequent decades of adult life. This developmental process has to be understood in regard to the impact of both illnesses and their treatment.
5. As a consequence of these issues the requirement for children to be cared for by staff trained in their particular needs and conversant with their pattern of disease has increasingly been reflected in the way health services are structured. This has led not only to the emergence of paediatrics as a general area of specialisation but also to the development of a range of specialist children’s services, specific to the whole spectrum of clinical conditions – respiratory, cardiac, neurological, orthopaedic, immunological and many others – at least as extensive as that in adult medicine or surgery.
6. The need for children to be able to access specialist care is self evident. The challenges faced in providing such care are very real, not least because the number of children requiring highly specialist care within any given specialty is often small.

7. Around 30,000 adults develop cancer each year in Scotland compared with fewer than 200 children and young people. The same pattern is seen across many specialty areas. This lower activity level in no way reduces the need for the individual patient to have access to specialist expertise and facilities, but it does create a different set of problems from those facing many aspects of adult medicine which often relate to high volume and demand, particularly with an ageing population.
8. In practice the specialist consultant base for many paediatric medical specialties is fewer than 10 across the country and, in a number of specialties, is fewer than five. Many specialist nurses and allied health professionals (AHP) work as single-handed practitioners, or in very small teams.
9. These issues present very practical challenges for the sustainability, accessibility and equity of services:
 - Small services and a limited specialist workforce are inherently vulnerable. Loss of a single member of staff can threaten service provision.
 - Individual NHS Boards, and in some specialties whole regions, are not self sufficient in service provision.
 - Maintaining service provision, particularly out of hours, may be impractical at a local or even regional level.
 - Training capacity in Scotland, or even across the UK, is proportionally restricted in ways that can affect staff development, availability and recruitment.
 - Peer support, education and professional development are difficult.
 - Economies of scale in terms of staff and facilities are more difficult to realise, with implications for service cost and investment.
 - Service accessibility may require travel – either by the patient (and family) to the specialist centre, or by staff to support local services, both of which raise problems that must be addressed.
 - Providing an appropriate level of local service, particularly in District or Rural General Hospitals, requires staff to develop a range of specialist expertise. Maintaining, refreshing and replacing such expertise can be difficult both for the organisation and the individual practitioner.
10. Historically these issues have manifested themselves, and been addressed, differently across the country, giving rise to inequity of service availability, accessibility and quality. While recognising the importance of ensuring local services are developed in ways that reflect local need, the challenges facing specialist children's services will always require solutions that involve collaborative approaches across NHS Board and regional boundaries.
11. Vital though such collaborative approaches are, they are not without their own challenges in respect of:
 - Maintaining integration from specialist care through to community-based local services.
 - Co-ordinating planning, prioritisation, service development and resource allocation.
 - The employment and deployment of staff across organisational boundaries.
 - Governance and accountability.

12. In addition to these issues, which arise as a result of activity patterns, there are a number of specific challenges emerging as a consequence of changing patterns of disease, improving outcomes or planned service change.
- The incidence of some conditions is increasing:
 - Type 1 diabetes in childhood has risen threefold since the 1970s.
 - Crohn's disease in children is four times more common than 20 years ago.In both these conditions Scotland now has one of the highest incidences in Europe.
 - Welcome improvements in survival are increasing and changing service demand:
 - Around 1 in 3 very low birthweight babies will be disabled, half of them severely, and will require life-long and often complex care.
 - A range of conditions, previously considered life-limiting within childhood, are displaying improved survival rates into adult life. This progress is not always matched with patterns of service provision within adult services that offer continuing care.
 - The move of the upper age limits for children's services from the 13th to the 16th birthday, recommended in the *National Framework for Service Change in the NHS in Scotland*, represents a positive step forward in the provision of age appropriate care. However, it will bring challenges both in terms of the shift in activity and, in some specialist services, the need to address patterns or manifestations of disease previously infrequently seen in paediatric practice.
13. These issues, significant in their own right, exist within an environment of wider service pressures particularly in regard to medical staffing. Changes in the career structures and employment arrangements for medical staff in training are currently creating instability in the overall staffing framework for paediatric services upon which all the individual specialist services depend. This is most immediately affecting the District General Hospital (DGH) children's services but also impacts on the specialist hospitals.
14. All of these issues bring with them the need for a proactive and co-ordinated response from within the NHS in Scotland. This must engage local, regional and national service planners and providers and be directly influenced by the needs and views of children, young people and their families.



2

Planning for Change

NATIONAL DELIVERY PLAN – PLANNING FOR CHANGE

15. In response to the pressures and challenges facing specialist children's services and the recognised desire to address these issues in a collaborative and equitable manner across Scotland, the National Steering Group for Specialist Children's Services was established in 2006.
16. Building on earlier work, including a previous review of Tertiary Paediatric Services (2004), and informed by clinical and organisational opinion regarding issues of immediate priority, the National Steering Group initiated a range of workstreams looking at both individual specialist services and cross-cutting themes (Table 1). The reports generated by the various workstreams can be accessed on the National Steering Group website www.specialchildrensservices.scot.nhs.uk

Table 1 – National Steering Group Workstreams

Clinical Specialties	Cross-Cutting Themes
Gastroenterology	Planning and Commissioning
Cancer	Workforce
Dermatology	Models of Care
Endocrinology	Age Appropriate Care
Complex Respiratory	Telemedicine
Critical Care	Remote and Rural
Inherited Metabolic Disease	
Rheumatology	
General Surgery of Childhood	

17. Although extensive, it was always recognised that the range of specialty services covered was ultimately selective. In part this reflected the fact that some areas of specialist children's services had either been the subject of recent separate reports and guidance including, in particular, Child and Adolescent Mental Health or were being considered within parallel workstreams addressing both adult and paediatric services, for example neurosciences and laboratory services.
18. The *National Delivery Plan* does, however, acknowledge and incorporate the requirement to undertake further work to ensure that issues of sustainability, access and quality are identified and addressed across the full range of specialist services for children and young people.

19. The proposed content of the *National Delivery Plan* was considered at a national conference in November 2007 and, subsequently, through consultation on a draft *Delivery Plan* launched in March 2008. Full details of the consultation exercise, the responses received and the Scottish Government's response can be accessed at www.scotland.gov.uk/nationaldeliveryplanconsultation and www.scotland.gov.uk/nationaldeliveryplanconsultationsummary.
20. The consultation demonstrated broad support for the *National Delivery Plan* and welcomed the significant investment being made available to enable real and sustained change. The challenges facing specialist children's services were seen to have been accurately represented and there was widespread agreement that the service needs identified for early action reflected immediate priorities.
21. Key issues raised through the consultation included the:
 - Need for clarity and confidence as to how additional resources would be applied to gain maximal and sustained benefit.
 - Magnitude of the workforce issues, both in terms of staff training and development and also recruitment and staffing levels.
 - Benefits of networks and the need to explore the further development of networked service models.
 - Value and potential increased role of telemedicine, particularly given the pattern of population and service distribution in Scotland.
 - Importance attached by young people themselves to age appropriate facilities, services and care.
22. The consultation also reiterated the clear desire, already recognised in the draft *National Delivery Plan*, to incorporate other specialty areas which have not been the subject of review, either through this or any parallel process, and which face similar challenges. Particular examples raised included; anaesthesia, radiology, surgical sub-specialties, asthma, palliative care and child protection.
23. The Scottish Government welcomes this consultation response, particularly given the breadth of contributions from across the NHS and, very particularly, from children, young people and their families. The results of the consultation have been incorporated into this *National Delivery Plan* and will continue to inform the work of the Specialist Children's Services Implementation Group which has been established to take this work forward.



3

A Service Model for Scotland

NATIONAL DELIVERY PLAN – A SERVICE MODEL FOR SCOTLAND

24. The provision of specialist care involves all sections of the NHS from primary care and community services to highly specialised national centres. Many aspects of local care will be developed and provided within the wider pattern of the child health services which are planned and delivered within each NHS Board area. However, if we wish to have a secure overall framework of specialist service provision for children and young people in Scotland, there is also a requirement to take a “whole system” approach and to agree and pursue a national vision within which local and regional services can develop and thrive.
25. This *Delivery Plan* sets out proposals designed to foster such a vision and to support a pattern of services, and an approach to service provision, that is:
- Planned
 - Sustainable
 - Collaborative
 - Accessible and equitable
 - Focussed on quality and patient safety
 - Adequately resourced

Planned Services

26. This *National Delivery Plan* lays out a clear aspiration for a pattern for specialist children’s services that is sustainable and accessible, integrated and of high quality and well and wisely resourced. These aspirations will only be achieved by careful planning.
27. The need for effective service planning is all the more important as the numbers of children in Scotland accessing specialist services are often relatively small, particularly compared with the demands of an ageing adult population. By way of example, for every one child with diabetes there are around 80 adult patients; rheumatic diseases, very common in the adult population, affect less than 1000 children across the country.
28. As a consequence, while it remains vitally important that local services are planned within individual NHS Board areas, there is a recognised need for specialist services, and even some elements of secondary care such as general surgery, to be planned on a regional or national basis. Regional Child Health Planning Groups are already in place and there is a requirement to continue to strengthen their role to ensure that they provide an effective forum for the co-ordination and development of services within the three regions. In addition, while recognising the need for regions to be able to respond to their own priorities, there is also a requirement for the three Regional Child Health Planning Groups to work closely together to ensure a broad equity of service availability and quality across Scotland.

29. There are, however, a significant number of specialist services for children where the patient population is sufficiently small to require a national approach to service planning and, in some specialties, service commissioning. The National Services Division (NSD) already plays a vital role through the commissioning of a range of nationally designated services (Annex A). This includes a number of very small volume services provided elsewhere in the UK.
30. NSD also oversees the establishment and operation of national Managed Clinical Networks which are playing a key role in the integration and development of specialist children's services (Annex B). As this service model is increasingly introduced there is a need to ensure that the pattern of individual Managed Clinical Networks is seen as part of a structured overall approach to specialist children's services – a 'network of networks'.
31. However, many elements of specialist services for children that would benefit from being organised on a national basis do not accord with the current criteria for national commissioning. Work is currently being undertaken by NHS Board Directors of Planning to bring forward proposals for revised national planning structures. Informed by this *National Delivery Plan*, once these revised structures have been agreed and introduced, it is intended that specialist children's services be an early priority.

We will:

Continue to support the work of the Regional Child Health Planning Groups and to encourage inter-regional collaboration where this will enhance service delivery.

Work through National Services Division to ensure that the existing and emergent pattern of nationally designated services and networks for children are taken forward as part of a 'whole-system' approach to specialist children's services.

Sustainable Services

32. The goal of high quality, safe and accessible services can never be delivered if services are vulnerable or inconsistent. One of the key priorities of service planning, particularly at a regional level, must therefore be the creation of service models that specifically and explicitly address sustainability.
33. This will involve:
- Identifying an achievable and sustainable balance between local services and specialist centres.
 - Creating supportive networks, including in-reach and outreach models, supported by staffing levels that facilitate such arrangements.
 - Providing appropriate training opportunities accompanied by well planned and adequately supported arrangements for the continued professional development of staff.
34. In practice much of the vulnerability in specialist children's services relates to workforce and the ability to recruit and retain staff, both for children's services in general and for speciality specific roles. Specialist services for children and young people, sometimes at a national level and frequently at a local level, are dependent on a small number of staff, or

- even isolated individuals, who have the necessary specialist expertise and training. That pattern involves the inherent risk that small changes in the staff profile can threaten sustainability, sometimes with little prior notice.
35. Current workforce planning, often for practical reasons, needs to address the broader generic issues across the clinical disciplines. In doing so it may not cover the very specific, but potentially critical, issues around service provision in individual paediatric specialties.
 36. Within most DGH settings, and to some extent in the specialist hospitals, support for specialist services is dependent on individuals, from across the clinical disciplines, who incorporate a specialist 'interest' into a more generalist role. Such specialist 'interests' may have been developed in response to specific service needs or may reflect the individual's existing area of experience and past training.
 37. Similar person and specialty-specific issues also arise in respect of University-based posts in the specialist hospitals where the special interest of the clinician significantly contributes to service provision but may not be replicated when the academic post is re-appointed.
 38. Unless these and comparable issues are clearly identified and addressed, particularly where a replacement is appointed, sustainability is immediately and often unintentionally threatened. This requires a level of workforce planning, locally and regionally, that:
 - Is sensitive to the specific requirements of individual specialties.
 - Is informed by an obligation to maintain an agreed pattern of specialist expertise.
 - Has flexibility to explore service-specific local solutions, e.g. up-skilling of existing staff, proleptic appointments, etc.
 - Adopts a multi-disciplinary approach that effectively utilises the potential contribution of all staff groups, including extended roles.
 39. Although particularly vulnerable to specialty-specific workforce issues, specialist children's services are also materially affected by wider generic workforce pressures.
 40. Changes in medical staff training, career structures and employment arrangements are already impacting on the maintenance of viable rotas in several services, particularly in DGH paediatric units. Current predictions envisage this situation worsening in the future.
 41. Given the central role played by DGH children's services in maintaining the accessibility of specialist services, as well as all aspects of secondary hospital care, early and effective solutions require to be identified and implemented. In some areas such solutions will necessarily require not just workforce solutions but also the creation of alternative sustainable service models.
 42. The delivery of specialist children's services frequently takes place across NHS Board, and sometimes regional, boundaries. Workforce planning needs to take account of such service models and to operate flexibly between different NHS organisations. The ability to do this effectively requires a shared approach to employment arrangements, particularly in respect to the specialist staff from various disciplines, often with advanced training and extended roles, on whom many specialist children's services depend.

We will:

Require Regional Child Health Planning Groups to ensure that sustainability is a specific element of all service development and redesign activity in children's services.

Work with NHS Education Scotland (NES) and other parties to develop staffing and service models that address emergent changes and pressures in medical staffing provision within children's services.

Ask the Scottish Workforce Information Standards System (SWISS) Programme Board to take specific account of specialist children's services in the future development of SWISS.

Seek agreement on the services, staff and competencies that should routinely be available to support specialist children's services within a District General Hospital paediatric unit.

Require NHS Boards and Regional Planning Groups, in conjunction with NES, to implement workforce development plans designed to ensure sufficient nursing and AHP staff, trained to advanced practice level, are available to support redesign and development within specialist children's services.

Monitor the grading of advanced nursing and AHP roles in specialist children's services across Scotland to ensure consistency of approach.

Collaborative Services

43. Although individual specialist services, at local and regional level, have often developed independently of each other, there has been, in recent years, both a recognition and a desire for a much more integrated pattern of working.
44. The concept of the Managed Clinical Network (MCN), introduced in the Acute Services Review in 1998, has been enthusiastically embraced within children's services such that a significant number of national and regional MCNs are already in existence (Annex B). The importance of the MCN as a vehicle for shared good practice, service development, data-gathering and audit and user engagement has been reinforced through the consultation on the *National Delivery Plan*. The consequent need to utilise the Managed Clinical Network model in a wider range of specialties, locally or nationally as appropriate, is recognised and will be progressed through the existing arrangements overseen by Regional Planning Groups and National Services Division.

We will:**Support the creation of national Managed Clinical Networks in:**

- **Cystic fibrosis**
- **Rheumatology**
- **Endocrinology and**
- **Complex Needs**

Request Regional Planning Groups to develop regional MCNs in line with the guidance in *Delivering a Healthy Future: an Action Framework for Children and Young People's Health in Scotland (2007)*.

45. Although heavily dependent on the input of clinical staff and service users networking also requires appropriate managerial, administrative and data-handling support. The capacity of MCNs, and other networked models, to realise their full potential across specialist children's services is therefore dependent on the existence of an effective support infrastructure with appropriate skills and resources.
46. There is particular merit in this support infrastructure operating across the boundaries of individual MCNs since this permits skill sharing, efficiency of resource use and sustainability of input while also reinforcing the concept that each individual MCN is part of a wider cohesive approach to an overall network of specialist children's services.
47. Regional network offices are already playing an important part in supporting both national and regional Managed Clinical Networks in children's services. Investment in the management and data-handling capacity within these offices will enhance the benefits which networks offer while also encouraging the integration of individual specialist networks into an overall 'network of networks' across services for children and young people.

We will:

Support the further development of network offices based on a model of regional hubs.

Invest in additional clinical, managerial and data-handling resource to enable MCNs to realise their full potential benefits.

Explore options to improve the information technology infrastructure for networks to assist data-gathering and analysis.

48. While MCNs have offered significant advances in enhancing the equity and quality of services, they do not provide a formal structure within which the organisation and development of services can be more directly managed. The devolution of increased authority in respect of resource use and service configuration would represent a significant shift both in the level of the integration within networked services and the relationship of these networks to other NHS structures at regional and local level.
49. Support for exploring such a model of a 'Managed Service Network' was clearly expressed through the consultation process for the *National Delivery Plan*. The Scottish Government is committed to reviewing the potential governance and operational implications of Managed Service Networks and to bringing forward proposals for consideration.

We will:

Bring forward, in 2009, proposals for the strengthening of network service models through the creation of "Managed Service Networks".

Pilot the Managed Service Network model in children and young people's cancer services in Scotland.

50. Good communication is central to the effectiveness of networks. Although initially established to facilitate clinical referrals the Scottish Paediatric Telemedicine Service has increasingly been utilised to support networking. This involves both specialist hospitals and local services (Table 2).

Table 2 Use of Video Conferencing to support Networks

Network	MCN/ Informal Network	Use of Video Conferencing
Genital anomalies	MCN	National MCN using video conferencing for executive meetings and clinical case discussion
Renal	MCN	National MCN using video conferencing for executive meetings and clinical case discussion
Child and Adolescent Mental Health	MCN	National MCN using video conferencing for executive meetings and clinical case discussion
Cancer Services	MCN	National MCN using video conferencing for executive meetings and clinical case discussion
Gastroenterology	Informal	Bi-monthly case discussion and education with multidisciplinary team
Child Protection	MCN	Regional MCN. Video conferencing used for executive group meetings and peer review meetings
Endocrine	Informal	Weekly multidisciplinary meeting
Palliative Care	Informal	Monthly multidisciplinary meeting
Inherited Metabolic Disease	MCN	Protocols Sub-Group

51. Further investment is required to extend and enhance the telemedicine infrastructure and its pattern of working. Accordingly, through this *National Delivery Plan*, resources will be made available over the next three years to improve the video conferencing facilities in the specialist children's hospitals and to ensure that all units and hospitals treating children have access to appropriate telemedicine support.
52. Investment will also be made available to strengthen technical support, provide training and develop roles which facilitate clinical involvement in telemedicine-supported care. This will not only strengthen networked service models but will also directly support the delivery of clinical care and service accessibility.

We will:

Make funding available to ensure that, based on the tiered model of the *Emergency Care Framework*, all the hospitals and units in Scotland treating children have supported access to appropriate telemedicine facilities.

Accessible Services

53. Accessibility is a fundamental measure of service quality. While patients and parents accept the requirement to travel to access elements of specialist care they also expect that whenever it is safe and reasonable to do so, services should be available at a local level.

54. These issues are particularly important for children, especially those requiring frequent or long-term care, where a requirement to travel to access care can cause substantial disruption to family life and education as well as creating significant financial pressures.
55. The commitments in this *Delivery Plan* to support the sustainability of services and to encourage networking will also foster accessibility. In addition, there will be a clear expectation on Regional Child Health Planning Groups, National Services Division and emergent national planning structures that the planning of specialist children's services should include local access as a key consideration in determining service configurations.
56. In practice, the availability of local services will depend on the skill mix and strength in depth of the local team and the capacity and willingness of specialist teams to support outreached and shared models of care. A significant priority for the resources being made available through the *National Delivery Plan* will be investments that support these aspects of services.
57. Some areas of Scotland face significant challenges due to their remoteness. Much of the work already being done through the Remote and Rural Implementation Group to identify and equip the most appropriate and sustainable pattern of service provision in these areas will be of benefit to specialist children's services. There is also a need for individual remote and rural services to be effectively networked with specialist children's hospitals as set out in *Delivering a Healthy Future*.
58. Telemedicine has a key role to play in enabling service accessibility, particularly in remote and rural situations. In addition to supporting clinical decision-making it also prevents professional isolation and facilitates staff development. The strengthening and extension of the Paediatric Telemedicine Service, which will be resourced through this *Delivery Plan*, will specifically seek to ensure that every location providing care for children has the capacity to benefit from effective telemedicine links. In investing this resource a key priority will be the creation of effective arrangements to support local clinical decision-making wherever possible.

We will:

Work with the Scottish Centre for Telehealth and the Remote and Rural Implementation Group to invest in telemedicine services that maximise support for local care, particularly in remote settings.

59. Accessibility also requires the existence of services to access. The welcome improvement in the survival of children with life-limiting, and often complex, conditions raises specific challenges. In the past children with such conditions frequently did not survive to adulthood. As a result training and service configuration in adult medicine is not designed to meet their needs.
60. This issue is not unique to Scotland but there is an accepted need to consider how arrangements could be put in place to better provide for these specific clinical scenarios.

We will:

Establish a working group to bring forward proposals for the long-term care of children with complex and life-limiting conditions.

61. The ability to access care can also be hindered by practical issues. Even where well-structured local services exist, there will inevitably still be occasions when children, young people and their families need to travel to access specialist care. In such circumstances it is important that:
- Episodes of care are well co-ordinated to make effective use of time and minimise travel.
 - Financial support is available to cover travel-related costs where necessary.
 - Adequate support, including parental accommodation, is available where inpatient care is necessary.
62. A number of children and young people with complex needs and disabilities depend on a range of aids and adaptations to their home environment if they are to maintain the best possible quality of life. There is a need to ensure that the arrangements by which such support is accessed are efficient and equitable.

We will:

Ask NHS Boards to consider the economic impact on families when making decisions about the care of children and young people.

Introduce a new system of financial assistance with structural adaptations for homeowners who are disabled or have disabled children, including children and young people, with complex needs and disabilities.

63. Access is particularly important for patients and families in vulnerable or disadvantaged social circumstances. The work regarding Specialist Children's Services needs to be taken forward in ways that reflect, incorporate or are aligned with the various initiatives being undertaken by the Scottish Government and other parties to address health inequalities as described in *Equally Well*, the report of the Ministerial Taskforce.

High Quality Services

64. There are many aspects of the specialist services currently provided to children and young people of which patients, families and the staff themselves can be justly proud. Healthcare, and very particularly specialist healthcare, is however always advancing and there is a constant requirement to review and develop services to ensure that they represent best practice and support the best outcomes for patients.
65. Many of the elements described in other sections of this *Delivery Plan* will directly impact on service quality – networks which support good practice and encourage audit; investment that makes services more accessible across the country; workforce planning that supports sustainability and prevents inconsistency.
66. Other steps are also necessary if we are to consistently achieve and maintain the highest quality of service.

Training and Education

67. The equipping of staff with the knowledge and skills to do their jobs well is key to service quality. This is particularly true where specialist expertise is required. Implementing the *Delivery Plan* successfully will depend on a pattern of well structured training and educational programmes designed to develop new roles, enable new ways of working and ensure all staff have the opportunity to maintain and enhance their skill base.
68. NHS Education Scotland are key participants in the development of the *Delivery Plan* and will be active partners in its implementation with the creation of a number of programmes specifically dedicated to the specialist children's services workforce. These will include:
- The creation of Managed Educational Networks to support developments in cancer, cystic fibrosis and other specialties.
 - Developing networks for Allied Health Professionals working in specialist children's services.
 - Building capacity in children and young people's psychological services.
 - Identifying and addressing specific training requirements for clinicians working in specialist children's services.
 - Specific work on stakeholder involvement and age-appropriate care.

Outcome Measures

69. In order to monitor progress and effectively manage change, there is a clear need to be able to measure outcomes. The complexity of specialist children's services, which encompasses the whole range of clinical specialties and disciplines, makes this challenging.
70. Within individual service areas there are agreed markers of service quality, for example; life expectancy, operative mortality, prescribing practices or readmission rates. Important though these parameters are, in many cases their usefulness in service development is limited by inconsistent or incomplete data collection, a dependence on long-term outcomes or uncertainty as to the extent to which the data gathered truly measures service quality.
71. There is, therefore, a need to be able to identify, gather and analyse a number of key clinical or service outcome measures that would allow an accurate and timely understanding of progress across the spectrum of specialist children's services. Work will accordingly be undertaken with Information Services Division and NHS Quality Improvement Scotland, in collaboration with professional bodies such as the Royal College of Paediatrics and Child Health, to agree additional realistic outcome measures that will support the implementation of the *Delivery Plan* and the longer-term development of specialist children's services.
72. It is also recognised that an additional area in which outcomes, and their analysis, are intended to be closely linked to service development and redesign is within individual Managed Clinical Networks. Audit is a fundamental precept of networked services. In support of this activity part of the investment in the infrastructure for MCNs will be targeted at strengthening the data handling and analysis capacity through regional appointments operating within the overall network support infrastructure.

Patient Safety

73. Improving patient safety is a recognised priority across many healthcare systems in the developed world. Recent years have seen a growing recognition of the significant impact that Healthcare Acquired Infection, medication errors and other adverse events have not only on individual patients but also in the resourcing and effectiveness of healthcare provision. These issues impact on specialist children's services in the same way that they affect other aspects of clinical care.
74. The NHS in Scotland is already committed to improving patient safety as reflected in the recent creation of the Scottish Patient Safety Programme and the Scottish Patient Safety Alliance. Although these initiatives have a necessary focus on the high volume of activity undertaken in the adult sector, arrangements will be put in place to ensure that specialist children's services are fully integrated into this work and that patient safety is recognised as a key driver of service change and development.

We will:

Support NHS Education Scotland to provide a range of educational and training opportunities targeted at sustaining high quality specialist services for children and young people.

Strengthen support for audit across the range of specialist Managed Clinical Networks for children.

Establish a working group involving Information Services Division, NHS Quality Improvement Scotland and relevant professional bodies to identify practical and meaningful outcome measures to support the monitoring of progress in specialist children's services.

Ensure that specialist children's services are integrated with, and benefit fully from, the Scottish Patient Safety Programme and allied activities.

Age Appropriate Services

75. The NHS in Scotland is already committed to moving the upper age limit for its children's hospital services from the 13th to the 16th birthday (with some flexibility up to 18 years). That change has been implemented in many hospitals, particularly at District General level, but will not be fully in place across the country until the new hospitals in Edinburgh and Glasgow are completed in 2013.
76. Along with the changes in age limits there is an accepted need to ensure that services and facilities for young people reflect their developmental stage in life. This issue is not exclusive to specialist services but children with complex or chronic conditions are inevitably high users of hospital services.
77. In addition to ensuring that hospital services give particular attention to the needs of young people, there is a parallel and equally important requirement that the transition of patients from children's services to care in the adult sector is well structured and patient focused. Inadequate provision for such transition can have serious consequences for the care of the young person and the management of their disease.

78. The importance of these issues is reflected in the fact that they are the subject of separate guidance which will be issued to the NHS in Scotland in the immediate future.
79. There is a specific need to ensure that all staff have access to appropriate training to enable them to interact effectively and appropriately with young people and to identify and address their particular needs. NHS Education Scotland had therefore been asked to undertake a Training Needs Analysis in regard to adolescent care. Once complete, this will inform the creation or identification of training programmes to be taken forward across all relevant clinical disciplines.

We will:

Publish separate guidance on hospital facilities for young people in Scotland.

Host a conference, in Spring 2009, to promote discussion and raise awareness regarding hospital services for young people.

Undertake, through NHS Education Scotland, a Training Needs Analysis in regard to adolescent care.

Require all NHS Boards to ensure, by 2013, that all staff routinely dealing with young people have had appropriate training.

Accommodated Services

80. Recent years have seen a significant investment in hospital facilities for children and young people. The new Royal Aberdeen Children's Hospital opened in 2004 and an improved and reconfigured paediatric unit, the Tayside Children's Hospital, was created within Ninewells Hospital in 2006.
81. In addition, there is ongoing work to enhance many of the children's units within the District General Hospitals throughout Scotland. By way of example, Crosshouse Hospital opened redeveloped facilities in 2007 and the planned new hospital in Larbert will also incorporate a paediatric unit serving the children of the Forth Valley area.
82. Beyond the above, the Government has committed to the reprovision of both the Royal Hospitals for Sick Children in Edinburgh and Glasgow (Yorkhill) within the next 5 years.
83. This major investment in new children's hospital facilities will not only create high quality environments designed to support the best of modern practice but will, for the first time, ensure that all the main inpatient units for children and young people in Scotland are located on sites which also support maternity and adult services.
84. This provides a unique opportunity to integrate specialist services across the spectrum, from the care of the mother and foetus to services for young adults. This will allow obstetric, paediatric and adult teams to work in closer collaboration than has previously been possible.

We will:

Support the provision of new children's hospitals in Glasgow and Edinburgh by 2013.

Encourage NHS Boards to ensure that full advantage is taken of the opportunities of co-location to improve services for children, young people and their families.

Resourced Services

85. The vision laid out for the future pattern of specialist children and young people's services is intentionally ambitious. The aim is to create a consistent pattern of high quality and safe services delivered in an equitable and accessible manner across the country.
86. While some of this can be achieved by redesign or redirected investment, we also recognise that there are a significant number of areas where the necessary changes require new resources to be made available.
87. The Scottish Government has therefore committed to investing £32 million over the next 3 years to support real and sustainable change. The prioritization of this major investment will be informed by the work of the Specialist Children's Services Implementation Group working under the auspices of the Children and Young People's Health Support Group.
88. The Implementation Group is charged to work closely with Regional Planning Groups, NHS Boards and National Services Division as well as NHS Education Scotland, NHS Quality Improvement Scotland and the Scottish Centre for Telehealth to ensure these additional resources produce the required changes and service developments consistently across the country.
89. Fuller details of the investment programme and the work of the Implementation Group are described elsewhere. The initial investment of £2 million for 2008/2009 has already been allocated in support of agreed early priorities. This investment is funding:
- New staff across the clinical disciplines.
 - New networks in specialties such as Cystic Fibrosis and Rheumatology.
 - Enhanced telemedicine facilities to support networking and education.
 - Increase planning capacity to ensure further investment is used effectively.
90. It is recognised that sustained improvements will require sustained support and the Government will ensure that the necessary long-term investment will remain in place to support services on which children, young people and their families can confidently depend.

We will:

Invest £32 million over 3 years to strengthen and develop specialist children's services across Scotland.

Ensure that this additional resource is used to create sustainable change and visible improvement in the quality and accessibility of services.



4

Immediate Priorities

NATIONAL DELIVERY PLAN – IMMEDIATE PRIORITIES

91. This *Delivery Plan* is designed to place the provision of specialist children's services to children and young people on a secure basis which supports a long-term pattern of service quality and consistency. Many of the initiatives are targeted at gaining medium and long-term benefit through improved planning, the creation of networks, workforce development and enhanced telemedicine links.
92. It is recognised that there are a number of services in which very early investment is required to create stability and enable rapid service improvement. Specifically these services are:
- Cancer Services
 - Cystic Fibrosis
 - Rheumatology
 - General Surgery of Childhood
 - Inherited Metabolic Disease
 - Gastroenterology and
 - Child and Adolescent Mental Health

Cancer Services

93. An extensive review of cancer services for children in Scotland was undertaken as part of the *Delivery Plan* review process. This work was in turn informed by the earlier report of the Children's Cancer Services in Scotland Working Group and the Guidance produced by the National Institute for Health and Clinical Excellence in 2005. This guidance described a tiered and integrated model of cancer services with specialist centres developing shared patterns of care with appropriately resourced local hospitals and units. Within such a model local care can be supported whenever possible while effective provision is made to access a specialist centre when required.
94. Application of this guidance is being taken forward by the recently established National Managed Clinical Network for Children and Young People's Cancer Services which commenced in 2007.

We will:

Support the continued development of the Managed Clinical Network for children and young people's cancer services and pilot the creation of a Managed Service Network.

Resource the children's cancer services in Glasgow and Edinburgh to provide the full range of specialist cancer care and to effectively support local shared care services in other centres.

Invest in Aberdeen, Dundee and agreed District General Hospitals to support their effective participation in shared care services in ways that reflect local demand and service configuration and maximise clinically appropriate opportunities for local care.

Maintain and continue to develop the national children's bone marrow transplantation service in Glasgow.

Cystic Fibrosis

95. There is acknowledged variability in the quality and accessibility of Cystic Fibrosis services for children across Scotland. Key determinants of outcome such as annual review and newer treatment options are inconsistently available and there is concern that long-term survival in Scotland does not match that of the best performing countries.
96. Much work has already been undertaken to identify the pattern of investment required, particularly in nursing and AHP staff, in order to bring services up to a uniformly high standard that accords with best practice. The immediate need is to develop a Managed Clinical Network, at a national level but with strong regional emphasis, which can foster equity of service across Scotland and inform the necessary further investment in service development.

We will:

Create a national Managed Clinical Network for Cystic Fibrosis in children.

Informed by the MCN, ensure a pattern of investment in Cystic Fibrosis services for children that supports agreed best practice.

Rheumatology

97. Although there is good evidence that early diagnosis, tight disease control and emerging treatments can prevent children with rheumatic conditions progressing to joint damage and disability, investment in these services has lagged behind other areas of the UK.
98. The specialist workforce is currently very small across all the involved disciplines with consultant medical input often depending on general paediatricians or adult rheumatology specialists with little direct training in paediatric rheumatology.
99. There is an agreed immediate need for an additional consultant post to support services across Scotland and for the creation of an MCN to take forward service developments.

We will:

Invest in an additional consultant post in Paediatric Rheumatology. Although based in the central belt this post will facilitate the support of networked services across the country.

Create a national Managed Clinical Network for Paediatric Rheumatology.

Support further developments to ensure equity of care across Scotland.

General Surgery of Childhood

100. Although specialist surgical procedures in children are chiefly undertaken in the main children's hospitals, surgery for more routine conditions has usually been performed in the District General Hospital, thereby maintaining local access.

101. Changes in surgical training and loss, through retirement, of senior general surgeons with paediatric experience, are increasingly threatening this pattern. In the absence of intervention the current trend could require many more children to travel to specialist hospitals for technically straightforward and low risk procedures.
102. Links are increasingly being created between the specialist centres and their regional District General Hospitals with a view to strengthening local surgical care. These arrangements require to be adequately resourced through the appointment of surgeons trained in the general surgery of childhood who have a regional remit to support local services.
103. There is a need for agreed pathways of care that bring consistency and clarity, particularly in emergency situations, regarding the respective roles of the local and specialist hospitals.
104. It is recognised that the delivery of good surgical services for children in a District General Hospital is greatly strengthened where there is a close working relationship between surgical staff and the in-house paediatric medical services. The maintenance of local surgical services will be dependent on the existence of such a whole team approach to this patient group.

We will:

Invest in additional consultant posts, working at a regional level, to support local general surgical services for children.

Publish care pathways to ensure the safe, consistent management of common surgical conditions.

Encourage effective collaboration between paediatric medical and surgical services within local hospitals.

Inherited Metabolic Diseases

105. Inherited Metabolic Diseases incorporate a complex range of specific, and sometimes very rare, inborn errors of metabolism. In a number of these the condition can have severe and life-limiting consequences, particularly where diagnosis is not made early and accurately.
106. There have been significant problems in the consultant and AHP staff profile in the services which has hindered equitable service delivery and threatened service continuity. The creation of a Managed Clinical Network (2007) and recent agreements regarding consultant appointments, have helped to stabilise service provision but there is a continuing need for further investment to ensure longer-term service stability and equity of quality and access.

We will:

Invest in additional medical and AHP staff to safeguard service provision in Inherited Metabolic Diseases.

Explore the potential contribution of extended roles (for example consultant dieticians) within Inherited Metabolic Disease services.

Gastroenterology

107. Paediatric Gastroenterology, Hepatology and Nutrition (PGHN) services are coming under increasing pressure in Scotland. This is due to recognised gaps in staffing and service provision; a reduction in the involvement of adult clinicians in the care of children and a significant and ongoing rise in the incidence of inflammatory bowel disease in children and young people. The impact of this latter issue is magnified by the progressive introduction of the raised age limit for children's services.
108. These issues were recognised in an earlier review of Tertiary Paediatric Services in 2004 and the present consultation exercise has drawn specific attention to the urgency with which some elements of service provision in Scotland require to be addressed.

We will:

Invest in an additional consultant post in PGHN to support services in the South East and Tayside Region.

Provide support to strengthen the paediatric gastroenterology network in the North Region.

Work with Regional Planning Groups to ensure appropriate investment in PGHN services across Scotland during 2009-2011.

Child and Adolescent Mental Health Services

109. A number of respondents raised issues about the delivery of Child and Adolescent Mental Health Services (CAMHS) and the potential to include funding for these services through the specialist children's services' workstream. The importance of psychological support for children and young people with serious or long-term conditions was also emphasised during the consultation exercise.

We will:

Make available additional funding during 2009 to 2011 to support the development of Child and Adolescent Mental Health Services.

Work with NHS Boards to improve the availability and accessibility of CAMH services.

Ensure that when investing in specialist children's services psychological support is recognised as a key component in the care of children and young people with serious or long-term conditions.



5

Planning for the Future

NATIONAL DELIVERY PLAN – PLANNING FOR THE FUTURE

110. This *Delivery Plan*, and the significant resources invested in its support, reflects the commitment of the Scottish Government to placing our specialist children's services on a sound and sustainable footing, fit for the future.
111. In order to ensure that the *National Delivery Plan* is taken forward, and the accompanying resources used to the maximum benefit of children and young people, a Specialist Children's Services Implementation Group has been established. The role, remit and membership of the Implementation Group is included in Annex C.
112. The Implementation Group will operate as a sub-committee of the Children and Young People's Health Support Group and will focus particularly on:
- The allocation of resources.
 - The identification and completion of additional workstreams.
 - Performance management.

Allocation of Resources

113. Informed by the immediate priorities, which were affirmed during the consultation on the *National Delivery Plan*, the investment of £2 million for 2008/2009 has been released to Regional Planning Groups and other provider organisations within the NHS in Scotland. Building on that encouraging start the major investment in support of the *Delivery Plan* will take place during 2009/2010 (£10 million) and 2010/2011 (£20 million).
114. It is essential that this very significant application of new resources is used to the maximum benefit of patients and is distributed across the specialties in a way that most effectively supports service development.
115. The Implementation Group will therefore establish a robust framework in which further investment can be prioritised. In allocating resources the Implementation Group will give priority to proposals that will:
- Support best clinical practice and offer maximum benefit to patients.
 - Enhance service sustainability.
 - Accord with the agreed priorities and policies of the NHS in Scotland.
 - Represent value for money.
116. This work will be progressed in close collaboration with Regional Planning Groups, National Service Division, NHS Education Scotland and the Scottish Centre for Telehealth. Informed by this *Delivery Plan*, and the further work of the Implementation Group, these organisations will be responsible for developing costed proposals for service developments.

Further Work

117. As acknowledged in this *Delivery Plan* the workstreams initiated by the National Steering Group did not encompass all specialties within children's services. Some services are already covered by national commissioning arrangements and others have been the subject of separate prior, or concurrent, work. For example, CAMHS and Emergency care are subject to separate implementation arrangements and frameworks.
118. The consultation for the *Delivery Plan* has however confirmed that there are a number of additional specialist services in which concerns regarding sustainability, quality or accessibility require to be understood and addressed. These include:
- Anaesthesia
 - Surgical Sub-specialties (e.g. ENT)
 - Palliative Care
 - Asthma and Immunology
 - Child Protection
 - Renal and Urology Services
 - Burns
 - Non-malignant Haematology
 - Radiology
 - Pathology
 - Non-interventional Cardiology
119. The Implementation Group will therefore require to consider those specialty areas not incorporated in the initial workstreams and to:
- Determine the availability of existing information regarding the service.
 - Scope what further work is required.
 - Agree arrangements by which such further work can most effectively be progressed.
120. In parallel there is a need to ensure that any outstanding issues raised through the original workstreams initiated by the National Steering Group have been fully considered. The aim will be to ensure that the implementation of this *Delivery Plan*, and the investment which accompanies it, adopts a 'whole system' approach to the provision and development of specialist children's services across the country.

Performance Management

121. It is essential that the investment in specialist children's services is used in ways that maximise patient benefit and effectively address the areas of priority concern regarding existing services. The Implementation Group will therefore be required to monitor implementation of the *National Delivery Plan* including the development of measures by which beneficial effect and added value can be satisfactorily demonstrated. This work will inevitably be synergistic with work on outcome measures described elsewhere in this guidance.

We will:**Ask the Implementation Group to:**

- **Develop a robust framework through which the investment in specialist children's services can be effectively prioritised and allocated.**
- **Produce and progress an action plan regarding the additional work required to ensure that resource allocation and service development takes appropriate account of the full range of specialist children's services.**
- **Work with other parties, including the Scottish Public Health Network, to seek to identify effective arrangements for the demonstration of actual and anticipated patient benefit arising from the increased investment in specialist children's services.**

CONCLUSIONS

122. *Better Health, Better Care* expressed the commitment of the Scottish Government to a National Health Service that supports local care wherever possible and provides timely, safe, effective and efficient services. Achieving these goals in respect of specialist services for children and young people poses very real challenges that require a coordinated response across the NHS in Scotland.
123. Much will be taken forward within local areas but the complex inter-dependencies that exist within and between the various specialist services for children and young people can only be addressed by also having a clear national perspective and effective collaboration between Regions, NHS Boards and individual service providers. Such an approach will not only support a consistent pattern of progress and improvement in the services we provide but will also ensure they are delivered in ways that address the inequalities of health and healthcare that still affect our society.
124. This *National Delivery Plan* sets out the pattern of investment and activity that is required to create real change in the sustainability, quality and accessibility of these services.



Annexes

ANNEX A

Children's services planned and delivered at a UK and Scotland level

SPECIALIST CHILDREN'S SERVICES – SCOTLAND	
Autologous ear reconstruction	Interventional and neonatal cardiology
Bone Marrow Transplantation	Interventional fetal therapy
Cardiac surgery	Molecular Genetics
Cochlear implantation	Musculoskeletal Sarcoma Surgery
Cleft Lip and Palate	Newborn blood spot screening
Complex airways management	Obstetric brachial plexus surgery
Extra Corporeal Life Support	Paediatric Intensive Care
ICU Retrieval	Pulmonary hypertension
Inpatient psychiatry (children to age 12)	Renal Transplantation
SPECIALIST CHILDREN'S SERVICES – UK	
Alstrom syndrome	Pancreas islet cell transplant
Ataxia telangiectasia	Persistent hyperinsulinaemic hypoglycaemia of infancy
Autoimmune paediatric gut syndrome	Rare neuromuscular disease
Bladder extrophy	Rare mitochondrial disease
Child and adolescent gender identity development	Retinoblastoma
Complex neurofibromatosis Type 1	Reconstructive surgery for congenital malformation of the genital tract
Complex tracheal disease	Secure forensic learning disability and mental health services for children and adolescents
Craniofacial surgery	Severe combined immunodeficiency disorder
Ehlers Danlos	Small bowel transplantation
Epidermolysis bullosa	Specialist liver disease (including transplantation)
Heart, heart/lung transplantation	Stem cell transplantation for juvenile idiopathic arthritis and connective tissue disorders
Lysosomal storage disorders	Vein of Galen ¹
Mental health services for deaf children and adolescents	

¹ Part of the UK service is provided at RHSC Glasgow.

ANNEX B

Managed Clinical Networks for Children and Young People's Services in Scotland (2008)

MANAGED CLINICAL NETWORKS	
National	Regional
Bone and soft tissue sarcoma	Child protection (West of Scotland)
Burns care	Child Sexual Abuse (SEAT) ²
Children and young people's cancer ¹	Gastroenterology (North)
Cleft Lip and Palate	Neurology (North)
Complex Care ²	
Complex child and adolescent mental health services	
Cystic fibrosis ²	
Paediatric epilepsy	
Endocrinology ²	
Genital anomalies	
Home parenteral nutrition	
Inherited metabolic disease	
Neurosurgery ¹	
Renal disease	
Rheumatology ²	
Scottish Muscle Group	

¹ Children and young people's cancer services and neurosurgery are also being developed as Managed Service Network pilots

² MCNs being introduced in response to the *National Delivery Plan* in 2008

ANNEX C

National Delivery Plan Implementation Group – Role, Remit and Membership

Background

The Review of Children and Young People's Specialist Services (formerly Paediatric Tertiary Services workstream) was established as part of the *Delivering for Health* agenda. This has been subsumed into *Better Health, Better Care* with the Children and Young People's Health Support Group identified as the main advisory group co-ordinating the activity identified in the Best Possible Start section.

The Implementation Group (IG) has been established as a sub-group of the Children and Young People's Health Support Group. The IG will be expected to provide advice on the implementation of this *National Delivery Plan for Children and Young People's Specialist Services in Scotland*.

Role and Remit

The IG will be expected to:

- Oversee the co-ordination of the process and proposals being developed for the implementation of the *National Delivery Plan*.
- Develop a prioritisation process for the bids in 2009/2010 and 2010/2011 including the development of an option appraisal framework against which bids are considered.
- Agree a process to identify and address those specialties not previously covered which require review.
- Ensure that outstanding work for specialties identified is completed against an agreed timescale.
- Ensure the outputs from the Directors of Planning review of the national planning arrangements within NHSScotland are taken into account.
- Develop clear communication links with key stakeholders to ensure ownership and role of IG members.
- Consider how implementation of the *National Delivery Plan* should be performance managed and benefits realisation assessed.
- Provide timely feedback to the CYPHSG on implementation of the *National Delivery Plan*.

Key Milestones

- Establishment of Implementation Group.
- Development of forward work programme.
- Publication of *National Delivery Plan*, Winter 2008/2009.
- Year 2 bids due, 31 December 2008 (for implementation 2009/2010).
- Year 3 bids due, 30 November 2009 (for implementation 2010/2011).

National Delivery Plan – Implementation Group

Membership

Caroline Selkirk (Chair), Director of Change & Innovation, NHS Tayside

Sharon Adamson, Chair, WOS Child Health Regional Planning Group

Jim Beattie, Scottish Officer, Royal College of Paediatrics and Child Health

Mary Boyle, Programme Director, NES

Michael Bisset, Clinical Director, Royal Aberdeen Sick Children's Hospital

Helen Byrne, Director of Acute Services Strategy, Implementation & Planning, NHS Greater Glasgow and Clyde

Lorraine Currie, Chair, Child Health Commissioners' Group

Fiona Dagge-Bell, Director of Patient Safety and Performance Assessment, NHS Quality Improvement Scotland

Eddie Doyle, Clinical Director, NHS Lothian

Myra Duncan, Regional Planning Director, South East and Tayside (SEAT) Regional Planning Group

Dr Andrew Eccleston, Paediatric Consultant, NHS Dumfries and Galloway

Deirdre Evans, Director, National Services Division

Stewart Forsyth, Medical Director, NHS Tayside

Annie Ingram, Director of Regional Planning and Workforce Development, North of Scotland Regional Planning Group

Heather Knox, Director of Regional Planning, West of Scotland

Derek Lindsay, Director of Finance, NHS Ayrshire and Arran

Mary Mack, Allied Health Professional - Children's Action Group

Jackie Sansbury, Director of Strategic Planning, NHS Lothian

David Simpson, Chair, Scottish Colleges Committee for Children's Surgical Services

Iain Wallace, Associate Medical Director, NHS Greater Glasgow and Clyde

John Wilson, Chair, SEAT Children's Regional Planning Group

Other representatives (to be confirmed)

Voluntary Sector

Staff Partnership

Scottish Government Advisors

John Froggatt, Deputy Director of Healthcare Policy and Strategy

Morgan Jamieson, National Clinical Lead for Children and Young People's Health in Scotland

Margaret McGuire, Interim Deputy Chief Nursing Officer

Louise Smith, Senior Medical Officer

Robert Stevenson, Head, Specialist Children's Services Team

ANNEX D

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ANNEX E

Glossary

AHP	Allied Health Professionals
CAMHS	Child and Adolescent Mental Health Services
CYPHSG	Children and Young People's Health Support Group
DGH	District General Hospital
ENT	Ear, Nose and Throat
IG	Implementation Group
MCN	Managed Clinical Network
NHS	National Health Service
NES	National Health Service Education for Scotland
NSD	National Services Division
PGHN	Paediatric Gastroenterology Hepatology and Nutrition
RHSC	Royal Hospital for Sick Children
SEAT	South East and Tayside
SWISS	Scottish Workforce Information Standards System
UK	United Kingdom
UN	United Nations

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