

# ENHANCING HEALTHCARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN NORTHERN IRELAND (FROM BIRTH to 18 YEARS)

# A REVIEW OF PAEDIATRIC HEALTHCARE SERVICES PROVIDED IN HOSPITALS AND IN THE COMMUNITY

**Consultation Document** 

5 November 2013

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# **Executive Summary**

# Introduction

- 1.1 This consultation document has been prepared by the Department of Health, Social Services and Public Safety (referred to in the document as "DHSSPS" or "the Department") following a review of healthcare services for children and young people in Northern Ireland. The Review was steered by a review team led by the Department and comprised of healthcare professionals. The purpose of the Review was to produce recommendations which will provide a strategic direction for the future development and enhancement of healthcare services in relation to the interface between hospital and community services for children and young people (from 0-18 years) over the next ten years starting from 2014.
- 1.2 The last comprehensive review of health service provision for acutely ill children and young people took place in 1999. Many changes have taken place since then which necessitate a closer look at current service provision for babies, children and young people (from birth to their 18<sup>th</sup> birthday) to ensure that treatment and care is of a high standard and is available to individuals and families when they need it.
- 1.3 The scope of this Review therefore relates to healthcare services. It is being completed in three phases. Phase One of the Review covers hospital services (supra regional, regional and area and local) and Phase Two covers community services. Both of these phases have been taken forward concurrently and are the subject of this consultation document.
- 1.4 Phase Three will cover palliative and end of life care for children with complex and life-limiting conditions and is being considered separately in order to give prominence to this important topic. The consultation document on Phase Three will be published in late 2013.

1.5 Following consideration of the responses received from the public consultation the Department intends to produce a final strategy for paediatric healthcare services covering the period 2014 to 2024. The strategy will incorporate the three phases of the Review and, subject to Ministerial approval, will be published by the Department in Spring 2014.

# **Review Methodology**

- 1.6 A Project Board/Review Group was established, made up of representatives from DHSSPS, Health and Social Care (HSC) Board (including Local Commissioning Groups), Public Health Agency, Royal Belfast Hospital for Sick Children and NI Children's Hospice.
- 1.7 In addition to the Project Board, an Expert Reference Group was drawn together to provide additional guidance and advice in the development of the review. The following organisations were invited to join the group:
  - Royal College of Surgeons
  - Royal College of Anaesthetists
  - Royal College of Radiologists
  - Royal College of Paediatrics and Child Health
  - Royal College of Nursing
  - Community Practitioners & Health Visitors Association
  - NI Medical and Dental Training Agency (NIMDTA)
  - Co-operation and Working Together (CAWT)
  - Public Health Agency (PHA)
  - Health and Social Care Board (HSCB)
  - Children in Northern Ireland (CINI)
  - Health and Social Care Trusts (HSCT), including the Northern Ireland Ambulance Service (NIAS)
  - HSC Local Commissioning Groups
  - Northern Ireland Commissioner for Children and Young People
  - Patient and Client Council (PCC).
- 1.8 Two independent expert "critical friends" were engaged to provide an independent overview of the review process:

- Dr Heather Payne Senior Medical Officer, Welsh Government; and,
- Fiona Smyth Royal College of Nursing.
- 1.9 During the development of the review, three focus groups took place to seek the views of children, parents and the voluntary sector and were set up with the help of the Participation Network and the Children's Outcome Group. The meetings of the focus groups took place as follows:
  - 5 November 2012 Newry children over 12 years with long term conditions such as diabetes and respiratory conditions and children who had left care;
  - 5 December 2012 New Lodge, Belfast children over 12 years who were generally in good health with no long term conditions; and
  - 11 December 2012 Antrim parents and the voluntary sector.
- 1.10 A DHSSPS team drafted the consultation document with input from the Project Board members and the Department's senior management team.

# Context

- 1.11 This Review document is about the commissioning and delivery of health services for children and young people from birth up to age 18 years. It sets out the strategic direction for the development of paediatric services over the next ten years.
- 1.12 Illness and injury in children and young people bring many challenges for parents, families and health service personnel. Children are not small-adults; they have the capacity to deteriorate very quickly when ill, and need to have treatment and care delivered to them in an age appropriate environment to meet their physical, emotional, social, educational and psychological needs.
- 1.13 There is a major link between the start a child gets in life and their future health and wellbeing. Therefore, we acknowledge the significant links between this Review and the DHSSPS Maternity Strategy (2012), and other public health strategies. The Review recognises that prevention, early

intervention and access to appropriate treatment, care and support are fundamental to the effective management of acute and long term conditions in childhood, and are consistent with the relevant Articles in the UN Convention of the Rights of the Child.

1.14 The Review promotes the earlier recognition of long term conditions and, consistent with long-term conditions in adulthood, it advocates an explicit focus for these within the commissioning of children's services. It also supports a care management approach for long term conditions in childhood that complements the strategic direction for the Integrated Care Partnership arrangements in adults which is also applicable to children.

## The Scope of the Paediatric Review

- 1.15 This document covers neonatology, paediatric medicine and surgery and specialist services i.e. elective (planned) and emergency services. As there is a separate consultation on paediatric congenital cardiac surgery, this is not included in this document. Nor is paediatric palliative and end of life care included, as given the importance of this topic, it is the subject of a separate consultation document which will be produced later this year. Mental health services for children and young people and maternity services also do not fall within the scope of this review as they are addressed in other Departmental documents; the Bamford Review sets the strategic direction for all mental health services, including those for children, and the Strategy for Maternity Care in Northern Ireland 2012-2018 sets the strategic direction for maternity services
- 1.16 The majority of children and young people are, and will continue to be, treated in the community, usually by GPs and other primary care professionals including nurses, midwives, health visitors, allied health professionals, community pharmacists and general dental practitioners. However, about 20% of children (from 0-15 years) access our emergency departments every year - the main causes being acute infection, abdominal pain and soft tissue injury.

- 1.17 There were 54,000 paediatric admissions to hospital in 2011/12 representing about 10% of all admissions under the acute programme of care. The largest category was for paediatric medical admissions representing some 41% of those children and young people admitted to hospital.
- 1.18 The needs of children, young people, their families and carers should be recognised in developing services. There is a need to provide children, young people and parents with appropriate information and support in the community to promote self management. This reflects the commitment in the Northern Ireland Executive's Programme for Government to ensure that people with a long term condition will be offered access to appropriate education, information and support programmes relevant to their needs, including innovative application of connected health. In addition, alternative models of urgent care will provide for enhanced access to services when needed, especially in areas of high deprivation.
- 1.19 As development of paediatric services proceeds, there will be more emphasis on community teams with input from a range of staff including the enhanced skills of nurses, and allied health professionals and support workers. This is essential if we are to manage the increasing number of children who are surviving the neonatal period, but who have a range of complex needs. A small but important number of these children are at greater clinical risk due to the nature of their condition, for example, through their requirements for ventilation support and enteral feeding.
- 1.20 Paediatric medicine and surgery are team based specialities. They are interdependent on other specialisms such as paediatric anaesthesia, imaging and intensive care. Technological advances and increasing sub-specialism in paediatrics together with a general shortage of skilled staff to maintain a 24/7 high quality service means that paediatric services cannot continue the way they are being delivered now.

## **Proposed Regional Paediatric Network**

- 1.21 The Review recommends the development of a regional paediatric network as offering the best opportunity to deliver paediatric services in accordance with the evidence of best practice and a "shift left" philosophy of "locally where possible specialist where necessary". It will be about a whole systems approach to change management for paediatric services provision and will help to ensure that children living across Northern Ireland have equity of access to high quality paediatric services.
- 1.22 The Department believes that to deliver this vision, the network should be constituted as an operational network, similar in role and function to the Critical Care Network for Northern Ireland (CCaNNI). This would help to ensure that paediatric resources, for example inpatient capacity, are used to maximum effect. The development of an operational network would also help to ensure that children from across Northern Ireland have equitable access to the tertiary paediatric services based in Belfast.
- 1.23 Service reform will require clinical leadership and engagement, and the further development of regional paediatric standards, different models of care, rota redesign, job planning, workforce development and implementation of agreed regional outcomes and audit.
- 1.24 A regional paediatric network will involve a range of commissioners and practitioners and agencies, and will facilitate staff to manage patients across traditional HSC Trust boundaries. This will mean that whilst all paediatric services may not be available at every hospital site more could be delivered locally without necessarily all services being centrally delivered.

# **Paediatric Services**

1.25 The review recommends that paediatric services should only be available on a site where there is an appropriate volume of cases and the relevant expertise available to deliver care safely and provide appropriate urgent cover. When a child needs to attend hospital they should receive the best possible care whether it is in an emergency department, on a hospital ward or in outpatients

- 1.26 No one size of model fits all in hospital or community settings. But future models of care should make progress towards consultant delivered care for those children who are ill or injured and need services.
- 1.27 While every effort will be made to support and sustain specialist paediatric services in Belfast, it is not possible to safely provide every specialist service and treatment in Northern Ireland and that this means children may have to travel to other parts of the UK for treatment.

## Age Appropriate Care

- 1.28 Children, from birth up to aged 16 years, should normally be cared for by a paediatric team in a paediatric setting. For young people between the ages of 16-18 years, choice and an age appropriate environment that also meets their clinical needs are essential for high quality care. Northern Ireland's HSC organisations are working to achieve this in order to deliver high quality care in line with best practice.
- 1.29 The Review proposes that there should be continued progress towards implementation of the General Paediatric Surgery and ENT standards which were published by the DHSSPS in 2010. This is a significant interim step to promote better services for children. Children under the age of 5 years should have emergency surgery undertaken in the Royal Belfast Hospital for Sick Children (RBHSC), unless the child's condition is time critical or the designated consultant general surgeon for general paediatric surgery is able to perform the operation within a time period appropriate to the child's clinical condition. Straightforward elective general paediatric surgery should continue to be delivered outside the regional centre in line with the 2010 DHSSPS standards.

- 1.30 There should be a clear distinction between general paediatric services and specialist (tertiary) services. The RBHSC will remain the centre for specialist paediatric services in Northern Ireland. The capacity for specialist paediatric services and general paediatric services in the hospital should be clearly defined to ensure equity of access to specialist paediatric services for children across Northern Ireland (NI) while protecting the general paediatric service for children in Belfast. The Royal Jubilee Maternity Hospital (RJMH) will remain the regional centre for neonatology.
- 1.31 Risk assessment in pregnancy will determine the best location for the delivery of a mother and her baby, in line with the recommendations of the DHSSPS Maternity Strategy (2012). Those babies at the highest risk need to be cared for in the regional neonatal intensive care unit (Royal Jubilee Maternity Hospital) located within the Belfast HSC Trust. This is to ensure that they have access to the highest level of neonatal consultant care and enhanced multi-professional service, including nurses, allied health professionals, social services and pharmacists.

# **Enablers for Change**

1.32 A number of enablers will be needed to progress change. This includes the enhancement of training, skills and continuing professional development of GPs, nurses, allied health professionals and other primary care practitioners. General (adult) surgeons who continue to operate and manage children unsupervised will need to be able to demonstrate ongoing surgical competence. Further enhancement of ICT systems will be required together with specific communication pathways to facilitate rapid expert opinion between local hospital and the tertiary centre, but also to provide enhanced local advice to GPs and other primary care practitioners to manage children better in their local communities.

1.33 The individual child or young person will have their own view on how their clinical care should be coordinated; but if we are to improve outcomes for children and young people it would be desirable to adopt an approach which establishes the following proposed key principles:

*Dignity* and *Respect* – that supports children and young people to make informed choices about their treatment and care (depending on their level of maturity), and their responsibilities regarding their own health;

*Health Improvement* – recognising that there is a need for paediatric services to be proactive in actively encouraging older children and adolescents to adopt healthier lifestyle choices and behaviours;

*Choice and flexibility* – recognising that no one "service" size fits all but that children and young people will be influenced by their level of maturity, clinical condition, and past experiences, and will have their own views on how/where to access services and inpatient facilities;

Accommodation and facilities – to be provided for the clinical needs of children and young people, and to support age appropriate educational, social and recreational activities;

*Educational* – recognising that paediatric services should be delivered in a way that meets clinical need but also minimises disruption to educational activities, where possible;

*Staff training and development* – those providing treatment and care to adolescents should be specifically trained to understand the clinical, social, behavioural and psychological needs of adolescents in order to improve health outcomes;

*Clinical Leadership* –children should have their care clearly coordinated by a team, normally the paediatric team but on occasions care will need to be led

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by the most appropriate clinical speciality who should have access to paediatric advice.

- 1.34 The following is a composite list of the Department's recommendations. These are explained in detail in Section E and are designed to improve the quality of healthcare for children and young people, and to improve the patient experience. Following consultation and analysis of responses the recommendations will be revised, as necessary, and a final paediatric strategy published by the Department in Spring 2014. This final document will also incorporate the results of the consultation on the paediatric palliative and end of life care.
- 1.35 The Health and Social Care Board and the Public Health Agency will be asked to take the initial lead to develop an action plan to progress the final recommendations. Some of these recommendations can be achieved relatively easily, others will take longer to achieve as they will require detailed planning, agreement and financial assessment of capital and revenue costs.
- 1.36 The recommendations have been grouped below under the following themes:
  - Enhanced primary and community care to improve outcomes and the patient experience;
  - Networked approaches to the delivery of paediatric services;
  - Age appropriate care;
  - Improving access to urgent and emergency treatment and care;
  - Improving the access and quality of General Paediatric Services
  - Improving the access and quality of Neonatal Services;
  - Children with Complex Physical Needs.

Enhanced primary and community care to improve outcomes and the patient experience

## Recommendation 1

Information and support provided for paediatric services should be reviewed and enhanced to ensure that the right information and support is available to children, their parents and families so that they may be actively involved in decisions about treatment and care, including self-management.

#### **Recommendation 2**

The Health and Social Care Board and Public Health Agency should work with GPs and other primary care and community care services to further improve access to primary and community care for children and families for those conditions which are more appropriately managed outside secondary care settings.

## **Recommendation 3**

The needs of children as well as adults should be recognised in developing services for people with long term conditions, including at transition to adulthood, and supported by improvements in connected health technologies.

# Networked Approaches to the Delivery of Paediatric Services

#### **Recommendation 4**

A regional paediatric operational network should be established to ensure equity of access to high quality services across Northern Ireland. The network would include commissioners, providers, clinicians and patient representatives and should work closely with the voluntary and community sector.

# Age Appropriate Care

# **Recommendation 5**

Children (from birth up to 16<sup>th</sup> birthday) should usually be cared for by the paediatric team in paediatric settings, and those aged 16-17 years should be managed in age appropriate settings within either paediatric or adult settings.

# Improving access to urgent and emergency treatment and care

# **Recommendation 6**

A paediatric model such as rapid response clinics, or short stay assessment and observation units, should be developed to allow rapid assessment and treatment by a range of skilled professionals, which avoids unnecessary inpatient admission. In addition the community children's nurses skill set should be further developed to provide them with skills in the rapid assessment and management of children who present with an acute medical problem.

# **Recommendation 7**

Children presenting to Emergency Departments should be cared for by staff with appropriate skills including paediatric basic life support and safeguarding training. At all times there should be:

- at least one member of staff trained to advanced paediatric life support standard or equivalent and one children's nurse or nurse with a core set of competencies and skills as set out in the RCN document 'Maximising Nursing Skills in caring for children in Emergency Departments' (March 2010);
- arrangements in place for immediate paediatric input to care, and,
- at least one member of staff who has received appropriate training in the management of child protection and child safeguarding issues.

Emergency Departments that accept children under 16 but which do not have paediatric on-site support, should have senior emergency department clinicians\* with skills to distinguish minor from more serious illness and injury, life support and stabilisation skills available at all times.

\*Associate specialist, staff grade, ST4 or higher, Advanced nurse practitioner or equivalent

#### **Recommendation 9**

Emergency Departments that accept children under 16 should have a paediatric resuscitation area with immediate access to children's resuscitation equipment and algorithms. Emergency Departments should also have a physical environment which separates children and young people from adults where possible.

# Improving the Access and Quality of General Paediatric Services

# **Recommendation 10**

Every child who is admitted to a paediatric department should be seen by a paediatric practitioner at ST 4\* or equivalent (including advanced children's nurse practitioner)<sup>1</sup> within four hours of admission and by a consultant within 24 hours of admission.

\*Assessment by St4 or equivalent within 4 hours of admission means that in practical terms there should be a St4 practitioner or higher resident in the hospital.

<sup>&</sup>lt;sup>1</sup> advanced nurse practitioner, staff grade or associate specialist doctor or Doctor in training at ST4 or higher

In order to further promote equity of access there should be clearly defined capacity for both specialist paediatric services and general paediatric services in the RBHSC. This is to ensure equity of access to specialist services for children across Northern Ireland and to ensure that children residing in Belfast can access general paediatric services in their local hospital.

#### **Recommendation 12**

The Health and Social Care Board and the Public Health Agency should support formal partnerships with other units in the United Kingdom or Republic of Ireland in order to provide support and sustainability of local service provision where safe and appropriate to do so.

**Recommendation 13** 

Within the proposed paediatric network there should be a surgical subgroup to support the safe delivery of paediatric surgical services across Northern Ireland in line with the DHSSPS standards for general paediatric surgery.

Improving Access and Quality of Neonatal Services

#### **Recommendation 14**

In establishing the paediatric network the formal relationship between the paediatric network, the neonatal network and Integrated Care Partnerships should be considered in order to establish firm linkages.

The Health and Social Care Board and the Public Health Agency should work with the neonatal network to develop a service specification for the regional neonatal intensive care unit, local neonatal units and special care units to meet the needs of local populations.

# **Recommendation 16**

Babies with the most complex healthcare needs should normally be cared for in the regional intensive care unit, Royal Jubilee Maternity Hospital (RJMH), including those under 27 weeks gestation and 1,000g at birth in order to ensure that they have access to the highest level of consultant care and associated services.

# **Children with Complex Physical Needs**

# **Recommendation 17**

The Health and Social Care Board, Public Health Agency and Health and Social Care Trusts working with the paediatric network should put in place a "step-down" programme of care to facilitate the earlier discharge of children with complex health needs into their local community.

# **Recommendation 18**

All medical and dental staff who regularly provide care for children should include child health in their annual appraisal.

The Department should work with regional medical, nursing and allied health professional training providers to ensure that workforce planning and training reflect service needs for children.

# **Imaging and diagnostics**

**Recommendation 20** 

The Health and Social Care Board should work with the Health and Social Care Trusts to ensure regional availability of paediatric radiology expertise, including out of hours.

# Information Communication and Technology (ICT)

**Recommendation 21** 

In taking forward the implementation of the ICT Strategy, the Health and Social Care Board should ensure that the requirements of paediatric services are included in ICT projects where appropriate.

# Research

# **Recommendation 22**

The paediatric network should work with clinicians and academics to develop research resources.

**Robust Outcomes Data** 

**Recommendation 23** 

Data collection systems, including agreed definitions, should be put in place to better manage demand, capacity and outcomes of paediatric services.

# Section A: The Importance of Paediatric Services and Drivers for Change in Service Provision

# Why a Review of Paediatric Services?

- 2.1 The last comprehensive review of health service provision for acutely ill children and young people took place in 1999<sup>2,3,4</sup>. Many changes have taken place since then which necessitate a closer look at current service provision for babies, children and young people (from 0 to their 18<sup>th</sup> birthday) to ensure that treatment and care is of a high standard and is available to individuals and families when they need it.
- 2.2 Children and young people deserve the best start in life. Good health enables a child or young person to make the best of opportunities that are presented to them, for example in social, cultural, educational, sporting and future employment chances. A good start in life assists in the development of healthy adults and enables individuals and families to contribute more widely to society.
- 2.3 In 2012, the DHSSPS published a *Strategy for Maternity Care in Northern Ireland 2012-2018*<sup>5</sup>. This recognised that the prospects for a healthy child begins long before the baby is born, at the pre-conceptual stage, and is strongly influenced by the start a child gets in life from its parents. The maternity strategy sets out 22 objectives to reduce risk and improve the life chances for all mothers and babies in Northern Ireland.
- 2.4 The Department now wants to move forward to the next stage of health service provision for children and young people; therefore, we are reviewing paediatric healthcare services. The aim of this Review is to further enhance the safety and quality of paediatric service provision, to improve health outcomes for children and young people, and to support children and their

<sup>&</sup>lt;sup>2</sup> DHSSPS, Hospital Services for the Acutely III Child in Northern Ireland 1999

<sup>&</sup>lt;sup>3</sup> DHSSPS Nursing Services for the Acutely III Child in Northern Ireland 1999

<sup>&</sup>lt;sup>4</sup> DHSSPS Paediatric Surgical Services in Northern Ireland 1999

<sup>&</sup>lt;sup>5</sup> DHSSPS A Strategy for Maternity Care in Northern Ireland 2012-2018 (July 2012)

parents to make informed decisions and choices regarding their treatment and care.

- 2.5 In doing so we want to acknowledge that children, young people and parents are partners in health service provision. Paediatric services are part of a continuum of Health and Social Care (HSC) provision which has many interrelated strands to promote healthy lifestyles, protect and maintain health and wellbeing, and provide the support needed for those living with poorer health, and social, economic and environmental disadvantage.
- 2.6 HSC Services for children and young people broadly covers:-

<u>Healthy Child, Healthy Future<sup>6</sup> programmes</u> – providing universal services to children – for example, enhancing child development, promoting uptake of immunisation and screening programmes, supporting effective parenting and promoting good nutrition;

<u>Early intervention</u>-identifying risk factors and tackling emerging health problems – for example, smoking in pregnancy, social, emotional and economic deprivation, domestic violence, poor parental mental health, substance misuse and poor sexual health.

<u>Primary Care Services</u> – largely delivered by GPs and other primary care practitioners such as dentists, pharmacists and optometrists usually when the child (or their parent) presents with a particular concern, trauma or illness;

<u>Community services</u> –usually services delivered by a team of professionals and linked to services in primary and hospital care (for example, services delivered by physiotherapists, nurses, counsellors, social workers and community paediatricians) to enable: a child to recover more quickly following a hospital admission; maximise support for long term conditions such as diabetes; or provide palliative and end of life care and support for the child and their family;

<sup>&</sup>lt;sup>6</sup> *Healthy Child, Healthy Future* A Framework for the Universal Child Health Promotion Programme in Northern Ireland DHSSPSNI 2010

<u>Hospital services</u> – such as emergency department, outpatient clinics, short stay assessment and treatment units and inpatient medicine and surgery. Some hospital services are provided for the whole region, usually based in the Royal Belfast Hospital for Sick Children, for example intensive care, complex surgery and specialist services for certain conditions such as cystic fibrosis;

<u>*Transition services*</u> – for children with healthcare needs who progress through adolescence and into adult health services.

#### What is the definition of a Paediatric Service?

- 2.7 For the purposes of this Review, we are concentrating on: acute hospital services to include general and specialist services; the management of transition of such services into adult services; and, the interface between hospital and community services. As a separate part of this Review we will publish later in 2013 a draft document for consultation on paediatric palliative and end of life care. Mental health services for children and young people also do not fall within the scope of this review.
- 2.8 By paediatric services we mean health services delivered to babies, children and young people from birth to their 18<sup>th</sup> birthday. This includes paediatric medicine which delivers general medical and more specialist care to infants, children and young people, for example, neonatology, long term conditions like asthma and coeliac disease, and paediatric intensive care. The Review also includes paediatric surgery, for example, general surgery for common conditions such as the removal of an appendix, to more specialist surgery for example, orthopaedics, trauma, neurosurgery, and ENT surgery. It also covers emergencies and attendance at emergency departments.
- 2.9 The healthcare needs of children and young people with complex conditions are also included in the Review. In doing so, we have looked at this from the perspective of the provision of general and specialist health services and the interface with community services. While the Review acknowledges the

importance of team based approaches to treatment and care, it does not go into the detail of, for example, safeguarding, social care, family support or reablement services as these are the subject of other documents (there is more on this in Section B below).

## What the Review is Aiming to Achieve?

- 2.10 The Terms of Reference for the Review are contained in Appendix A. In general the Review aims to:
  - Set out the strategic direction for the broad scope of paediatric medical and surgical services, and associated specialities, that should be available to the population of Northern Ireland, at <u>local</u> (i.e. closer to home), <u>area</u> (within a HSC Trust area), <u>regional</u> (at the Regional Children's Hospital i.e. RBHSC), and supra-regional (at UK or island of Ireland) levels;
  - Promote age appropriate paediatric services;
  - Recognise the developmental, emotional and psychological needs of adolescents in the planning and design of services and promote smooth transition to adulthood;
  - Explore new ways of working, develop an appropriate skills mix and team based approaches to paediatric care; and
  - $\circ$   $\,$  Make the best use of available human and financial resources.

# **Drivers for Change in Paediatric Services**

2.11 The Department believes that change is inevitable in paediatric services. This is because there are many drivers for change which have (and will continue to have) a direct impact on paediatric service provision over the next 5 to 10 years. Some of these drivers for change relate increasingly to service pressures and the need to reform and modernise all HSC services, but others are more particular to paediatric services.

- 2.12 There is therefore a real need to embrace change and manage it in a coordinated way which is the purpose of this Review. The Department believes that the recommendations arising from this Review will continue to deliver for Northern Ireland a quality, safe and sustainable service for children, young people and parents of the future.
- 2.13 The key drivers for change in paediatric healthcare service provision are:

• Changes in the numbers of children influence the needs for services. Increased numbers of births in recent years means that the 0-4 year old population has increased within the last 10 years;

• More children surviving preterm birth and congenital conditions due to screening, earlier intervention, the availability of highly skilled HSC staff, advances in medicine and the positive impact of technology<sup>7</sup>; however, some of these children have major disabilities and complex needs throughout their lives and therefore will require ongoing paediatric care;

• The negative impact of lifestyle and other factors on the health and wellbeing of children, with a rising number of children and young people having long term conditions with consequential potential negative impact on their health and well being unless identified early and managed appropriately, for example, obesity, diabetes, asthma, and allergies;

• The need to recognise the importance of individuals and families as partners in care with the provision of information to facilitate them to self manage their condition more effectively and with early access to advice and/or assessment when required, especially in an acute exacerbation; and as close as possible to home;

<sup>&</sup>lt;sup>7</sup> This would also include fetal medicine which specialises in the health of the unborn baby. It offers screening, diagnosis, and treatment of complications which may arise in unborn babies

• More sophisticated interventions and changing models of care so that common conditions can be managed as day cases and without the need for inpatient admissions;

• The recognition that there are interdependencies between some paediatric services and other HSC services, for example, access to laboratory and diagnostic services, anaesthetic services, intensive care, and psychological support are all fundamental components of some of the more specialist paediatric services;

• A UK shortage of paediatric specialists especially in some smaller paediatric sub-specialities leading to services not being sustainable in all areas and where single handed practice will not deliver high quality, sustainable care on a 24/7 basis;

• The need to ensure high quality training for doctors, compliant with European Working Time Regulations and with sufficient exposure to a larger caseload of patients to develop their expertise; this is essential to ensure that doctors and other health practitioners will be expert clinicians of the future;

• Team working and collaborative approaches to paediatric service provision is the way forward. This needs the recognition and enhancement of skills and competencies of practitioners such as children's nurses, advanced nurse practitioners, allied health professionals, GPs and other primary care professionals; and,

• Research, Enquiries<sup>8</sup> and evidence of good practice continues to change how services are delivered, with organisations such as the National Institute for Health and Clinical Excellence (NICE), General Medical Council

 <sup>&</sup>lt;sup>8</sup> Confidential Enquiry Maternal and Child Health; National Confidential Enquiry into patient outcomes and Death and The Child Health programme: Royal College of Paediatrics and Child Health (RCPCH) and the Maternal, Newborn and Infant programme: MBRRACE-UK.
 WWW.HQIP.Org.UK

(GMC), Nursing and Midwifery Council (NMC) and the Royal Colleges producing standards and guidance to promote safer and more effective treatment and care.

2.14 All of these drivers for change will impact on how paediatric services will be delivered in the future. There are also a number of Ministerial policies, strategies and frameworks, which impact on the general health and wellbeing of children and young people and on HSC provision. These are discussed in more detail in Section B.

# Summary

- 2.15 Section A outlines why a review of paediatric services is important for the health and wellbeing of children and young people. This Review follows on from a Review of Maternity Services (2012) by the Department and aims to provide babies, children and young people (birth to 18<sup>th</sup> birthday) with effective acute HSC services linked into community services.
- 2.16 There are many drivers for change which require a closer look at how paediatric services will be delivered in the future. Acute paediatric medicine and surgery are not stand alone specialities but are part of a continuum of HSC service provision, linked to other important public health messages and the protection of the most vulnerable children in society. The next section provides an overview of some of the most important strategic Government, including DHSSPS, documents which impact on the health and well being of children and young people.

# **Section B: Strategic Context**

# OUTCOME

*"Our vision is that children and young people living in Northern Ireland will thrive and look forward with confidence to the future".* 

# A Focus on Children and Young People

- 3.1 The Northern Ireland (NI) Executive<sup>9</sup> has said "*our vision is that children and young people living in Northern Ireland will thrive and look forward with confidence to the future*". This is a shared vision across all Northern Ireland government departments. For DHSSPS this is about working across government to;-
  - Improve health and well being outcomes;
  - Minimise health inequalities;
  - Deliver services of the highest quality; and
  - Provide a good patient experience when HSC services are used.
- 3.2 Following publication of the *Children and Young People's 10-Year Strategy<sup>10</sup>, (2006 2016)* the Office of the First and Deputy First Minister (OFMDFM) also led a programme on *Delivering Social Change<sup>11</sup>*. This programme is about tackling multigenerational poverty and improving children's health, well-being, educational and life opportunities. In addition, there are a number of priorities within the *Programme for Government 2011-2015<sup>12</sup>* which have a direct and/or indirect impact on the lives of children and young people In Northern Ireland. Of particular note is Priority 2 which is about *Creating opportunities, Tackling Disadvantage and Improving Health and Wellbeing.*
- 3.3 The NI Executive's vision for children and young people is underpinned by the United Nations Convention on the Rights of the Child (UNCRC)<sup>13</sup>. Whilst the standards of the UN Convention are not legally enforceable, in 1991, the UK

<sup>&</sup>lt;sup>9</sup> Our Children and Young People – Our pledge – a ten year strategy for children and young people in Northern Ireland 2006-2016; Office of the First and Deputy First Minister

<sup>&</sup>lt;sup>10</sup> Our Children and Young People – Our pledge – a ten year strategy for children and young people in Northern Ireland 2006-2016; Office of the First and Deputy First Minister

<sup>&</sup>lt;sup>11</sup> Delivering Social Change: Children and Young Persons Early Action Document 14 November 2012 OFMDFM

<sup>&</sup>lt;sup>12</sup> Programme for Government 2011-15

<sup>&</sup>lt;sup>13</sup> UN Convention on the Rights of the Child 1989

Government committed itself to working towards the realisation of the rights of children.

3.4 There are 54 articles within the UNCRC. Some articles are especially relevant to policy development and service redesign. Article 3 of the UN Convention encourages institutions to make the best interests of children a primary consideration in all action affecting them. Article 12 is about children having the right to say what they think should happen; Article 23 is about children with disabilities and, of particular importance to this Review, Article 24 is about health and health services. This states that children have a right to good quality health care.

# Linkage to other DHSSPS Strategic Documents

- 3.5 While the focus of this document is about good quality health care for children and young people needing paediatric medicine and surgical services, it is acknowledged that there are a range of other documents which have recently been published (or are about to be published) by DHSSPS which go towards fulfilling some of the goals outlined in paragraph 3.1 above.
- 3.6 An overview of the strategic documents which will contribute to the health and wellbeing of children and young people are set out in Appendix C. While all of these documents are important in their own right, there are three particular strategic priorities which have major links with this Paediatric Review. These are:

Transforming Your Care (2011)<sup>14</sup>;

*Quality 2020 (2012)*<sup>15</sup>;

E-Health (which is ongoing); and,

Draft Service Framework for Children and Young People (which is ongoing).

<sup>&</sup>lt;sup>14</sup> Transforming Your Care: A review of Health and Social Care in Northern Ireland: Health & Social Care Board December 2011

<sup>&</sup>lt;sup>15</sup> Quality 2020 <u>A 10-YEAR STRATEGY TO PROTECT AND IMPROVE QUALITY IN</u> HEALTH AND SOCIAL CARE IN NORTHERN IRELAND: DHSSPS November 2011

The following paragraphs provide more detail on how they link with the Paediatric Review.

- 3.7 Transforming Your Care (TYC) is a major review of Health and Social Care in Northern Ireland and was published in December 2011. This pivotal document sets out ninety nine recommendations for reform and modernisation of health and social care services, including paediatric services. TYC proposes a model which puts the individual at the centre of the health and social care system, with the model built around what will produce the best outcomes for individual users, carers and families.
- 3.8 TYC contains twelve principles which underpin any HSC service change; these are included in Appendix D. Consultation on '*Transforming Your Care – Vision to Action*', published in October 2012 sets out, in more detail, how reconfiguration will be achieved.
- 3.9 TYC has a number of child health recommendations such as the need for a review of inpatient paediatric services to include palliative and end of life care, and the establishment of formal partnerships outside the jurisdiction of Northern Ireland for very specialist services.
- 3.10 Other proposed elements which are relevant to the Paediatric Review are:
  - A focus on health promotion, disease prevention and early intervention;
  - Enabling people to live as healthily and independently as possible to include the use of self directed support and the promotion of individual budgets;
  - Formation of seventeen Integrated Care Partnerships to support and enable primary, hospital and community services to work more effectively. For example, in long term conditions management; recommendation 43 states – "close working between hospital and community paediatricians through Integrated Care Partnerships;
  - A proactive approach to long term conditions, to include self education and self management;
  - Shifting HSC services closer to home, with the further development of the primary and community infrastructure in a revised hub and spoke model;

- Effective use of technology, for example tele-health and tele-care;
- Fewer emergency and elective hospital admissions, reduced length of stay and fewer hospital beds;
- Reconfiguration of acute hospitals using specific criteria (see below) with a focus on networked hospital service provision;
- Establishing Family Nurse Partnerships for women (aged 19 and under) to improve the health and wellbeing of their new babies and family members, and to prevent social exclusion;
- Embedding Family Support Hubs to focus on early interventions, positive parenting, and speech, language and communication skills;
- Promotion of inter-agency, multi-disciplinary and cross-professions emphasis on Safeguarding Children and promoting their welfare as well as affording them protection;
- Promotion of partnership approaches to prevent children having to be separated from their families, where possible;
- Implementing the DHSSPS Maternity Strategy 2012 to normalise birth and reconfigure maternity services based on the best available evidence;
- Enhancing Northern Ireland Ambulance Services to provide alternatives to going to hospital and support people to safely manage their health at home, where appropriate, and take patients to the most clinically appropriate destination;
- Enhancing the dedicated paediatric and neonatal transport service;
- Ensuring effective safe, sustainable arrangements for Paediatric Congenital Cardiac Surgery and Paediatric Interventional Cardiology; and,
- Increasing Northern Ireland's health service links with the Republic of Ireland and Great Britain.
- 3.11 *Transforming Your Care (TYC)* does not go into detail on the provision of paediatric medicine or surgical services but expects this Review to facilitate a regional approach as to how services should be organised in the future; this includes palliative and end of life care for children and young people.

- 3.12 Of particular note in *Vision to Action* are the TYC draft criteria for the reconfiguration of any acute service in Northern Ireland. More detail on these criteria is contained in Appendix E, but they include weighted criterion on:
  - Safety and Quality;
  - Deliverability and sustainability;
  - Effective use of resources;
  - Local Access; and,
  - Stakeholder support.
- 3.13 The consultation on TYC closed in January 2013, and the post consultation report<sup>16</sup> was launched by the Minister in a statement to the Northern Ireland Assembly on 19<sup>th</sup> March 2013 at which he also set out the way forward for implementation.
- 3.14 Quality 2020 is another key strategic document which relates to the quality and safety of services. Safety and quality underpins all health and social care services. 'Quality 2020', published in November 2011 sets out a strategic framework and plan of action that will protect and improve quality in health and social care over the next ten years. The focus on safety and quality has several drivers, including the outcomes of local, national and international research, the dissemination of best practice within and between systems, and the increasing demand from the public for improvements in the quality of services. There have been major developments in evidence-based standards and guidelines over the past few years, many of which have been endorsed as best practice by the DHSSPS. NICE guidance and regional standards such as DHSSPS Service Frameworks will lead to more consistent, evidence-based practice. The Department's ten-year *Quality 2020 Strategy* identifies quality under three main headings:
  - <u>Safety</u> avoiding and preventing harm to patients and clients from the care, treatment and support that is intended to help them; it also

<sup>&</sup>lt;sup>16</sup> <u>http://www.tycconsultation.hscni.net/wp-content/uploads/2013/03/Transforming-Your-Care-Vision-to-Action-Post-Consultation-Report.pdf</u>

includes learning from, and changing practice as a consequence of adverse events, complaints and inquiries etc.;

- <u>Effectiveness</u> the degree to which each patient and client receives the right care (according to scientific knowledge and evidence-based assessment), at the right time, in the right place, with the best outcome; and
- <u>Patient and Client Focus</u> all patients and clients are entitled to be treated with dignity and respect and should be fully involved in decisions affecting their treatment, care and support.

A full *Quality 2020* implementation plan is in place; this work is led by the Public Health Agency in collaboration with the HSC.

- 3.15 **E** Health The world is changing with new technological advances coming to the market every day for the general population. This is also true of health services where there is an increasing emphasis on maximising the potential that technology has to offer in improving health outcomes for the population of Northern Ireland. This is a strategic priority for the DHSSPS to maximise the use of new diagnostic and communication technology, to add value to individual service users and to provide an economic competitive advantage for society in Northern Ireland.
- 3.16 Information and communication technology (ICT) has many functions in the primary, community and hospital settings. This includes data collection and analysis to inform the planning, delivery, monitoring and evaluation of paediatric services, business administration and support for staff and delivering direct care to patients. The implementation of the Department's ICT strategy<sup>17</sup> continues to progress and is linked to the wider reform and modernisation of HSC services.
- 3.17 Clinical Standards and Inquiries there are a number of clinical standards/reports and major Inquiries, which have a direct or indirect impact on the outcome of this Paediatric Review. These include:-

<sup>&</sup>lt;sup>17</sup> DHSSPS Information and Communication Technology Strategy, 2005

- DHSSPS -General Paediatric Surgery Standards (2010);
- DHSSPS Paediatric ENT Standards (2010);
- RQIA -Review of Pseudomonas Aeruginosa Infection in Neonatal Units (2012);
- RQIA- Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards in Northern Ireland (2012);
- NCEPOD Report into children's surgery "Are we there yet?" (2011)
- DHSSPS- Children's and Young People's Service Framework (see paragraph 3.23 below); and,
- HSCB Review of Paediatric Congenital Cardiac Services (2013).

# 3.18 General Paediatric Surgery Standards in Northern Ireland (Children up to 13<sup>th</sup> Birthday) - in 2010, the DHSSPS issued Improving Services for General Paediatric Surgery – Policy and Standards of Care for General Paediatric Surgery in Northern Ireland<sup>18</sup>. These standards were derived from the work of the Children's Surgical Forum of the Royal College of Surgeons<sup>19</sup>. The standards issued for implementation in Northern Ireland distinguished between "elective" (i.e. planned surgery either inpatient or day case) and emergency surgery. In addition, it distinguished between the care of older children from that of children under the age of five years. It identified the environment in which surgery can be undertaken at local and regional levels, and the skills and throughput required to maintain a safe, high quality service. To date, the implementation of these standards across Northern Ireland has been variable.

<sup>&</sup>lt;sup>18</sup> DHSSPS General Paediatric Surgery – Policy and Standards of care for General Paediatric Surgery in Northern Ireland May 2010

<sup>&</sup>lt;sup>19</sup> The Children's Surgical Forum brings together a range of professionals involved in delivering surgical services to children. This includes representatives from the College, the surgical specialist associations, other medical royal colleges, the College's Patient Liaison Group and the Department of Health (London).

- 3.19 Standards for Paediatric Ear, Nose and Throat (ENT) Surgery (children up to 13<sup>th</sup> Birthday)<sup>20</sup> this document is linked to the general paediatric standards identified in paragraph 3.18 above. It too distinguished between "elective" paediatric ENT surgery and emergencies, and the care of older children from the care of those under the age of 6 months.
- 3.20 Review of Pseudomonas Aeruginosa infection in Neonatal Units this Review was commissioned by the Minister for Health, Social Services and Public Safety in January 2012, following outbreaks of pseudomonas infection in some neonatal units. Tragically, some newborn babies died. The Review which was led by the Regulation and Quality Improvement Authority (RQIA) looked at the circumstances leading to the incidents and the effectiveness of the HSC responses. An interim report was published in April 2012 with a final Report published at end May 2012<sup>21</sup>. In all, thirty two recommendations were made which were accepted by the Minister. Several recommendations related to surveillance arrangements, and the prevention and control of infection in the neonatal units; others related to governance and communication at regional and local levels. In addition, there were specific recommendations regarding improvement in accommodation in neonatal intensive care in certain HSC Trusts, the development of a region -wide neonatal network, and the extension of the hours of availability of a neonatal transport service. Implementation of all the recommendations is underway in all HSC organisations.
- 3.21 Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards - the RQIA published a report<sup>22</sup> in December 2012 on the provision of care to children under the age of 18 years admitted to adult hospital wards. Between 2009 and 2010 there were nearly 4,000 children admitted to adult wards, mostly aged 15-17. Whilst the Review found examples of innovation and good practice, it highlighted the need to ensure that such practice was shared amongst HSC Trusts. In addition, it found that there was no

<sup>&</sup>lt;sup>20</sup> DHSSPS: Paediatric ENT surgery in Northern Ireland – Policy and Standards of Care for Paediatric ENT surgery in Northern Ireland – May 2010

<sup>&</sup>lt;sup>21</sup> RQIA Independent Review of Incidents of *Pseudomonas aeruginosa* Infection in Neonatal Units in Northern Ireland Final Report 31 May 2012

<sup>&</sup>lt;sup>22</sup> RQIA Baseline Assessment of the Care of Children Under 18 Admitted to Adult Wards in Northern Ireland December 2012

standardisation of the age limits across hospitals to which children were admitted to paediatric wards. The RQIA Report made fourteen recommendations for improvements to service delivery.

- 3.22 Are we there yet? A Review of Organisational and Clinical Aspects of Children's Surgery<sup>23</sup> - this UK document considered the changes in paediatric surgery over the last 20 years, for children under the age of 18 years. It highlighted the reduction in the number of operations being undertaken in local hospitals with an increasing tendency to refer children to a tertiary centre, and its associated consequences. It made recommendations to improve the safety and quality of services to include the reorganisation of care, and the importance of linkage to other paediatric, anaesthetic and interhospital transfer services.
- 3.23 Children's and Young People's Service Framework as part of a wider programme on service standards to promote high quality, safe and effective care, a Children's and Young People's Service Framework is being developed by the Department. This will set clear standards for the commissioning and provision of services for children and young people across health and social care. Each high level standard will be supported by evidence of effectiveness and a performance indicator which will gather baseline data on performance. The Framework will encompass social and medical models of care to include generic and specific standards for:
  - Improving birth outcomes;
  - Promoting child development across the life course;
  - Positive mental health for children and young people;
  - Children and young people with acute and long term Illness;
  - Children and young people with a disability; and
  - Children and young people in special circumstances.

Following consultation, and subject to Ministerial approval, it is anticipated that the final document will be published in mid 2014.

<sup>&</sup>lt;sup>23</sup> NCEPOD: Are we There Yet?- A Review of Organisational and Clinical Aspects of Children's Surgery: 2011 www.ncepod.org.uk

#### 3.24 Review of Paediatric Congenital Cardiac Surgery and Interventional

**Cardiology** - due to the complex nature of cardiac surgery in Northern Ireland, and the relatively low number of procedures carried out here, the HSC Board and Public Health Agency commissioned an Expert Panel's Review of Paediatric Congenital Cardiac Services<sup>24</sup>, based on the Safe and Sustainable Standards<sup>25</sup> developed for England. The Expert Panel's Report was published in August 2012. Following publication of the Expert Panel's report, the HSCB and PHA were tasked with establishing a working group to develop standards and options for the future provision of this service for Northern Ireland, taking account of the Expert Panel's report. A public consultation on the further provision of this service for<sup>26</sup> the population of Northern Ireland has been completed and a preferred way forward has been submitted to the Minister for consideration.

3.25 Given the wide consultation that was undertaken for the cardiac surgery review, this Paediatric Review will not reiterate its findings, but will make reference to it, where appropriate to do so.

#### **Summary**

- 3.26 This section explains the strategic drivers that will influence health services for children. It highlights the links between this Review and the UN Convention on the Rights of the Child, the NI Executive's commitments to children and young people, and the range of strategic documents, standards, inquiries and evidence which link to the wider health and wellbeing of children, young people and society.
- 3.27 Of particular relevance to this Paediatric Review is: *Transforming Your Care*, which sets out the need to reform and modernise all HSC services; and, *Quality 2020* which promotes the safety and quality of service provision. A range of standards derived from the best available evidence has also been

 <sup>&</sup>lt;sup>24</sup> HSCB: Review of the Paediatric Congenital Cardiac Services – Belfast Health and Social Care Trust: 2 July 2012
 <sup>25</sup> National Specialised Commissioning Group: Safe and Sustainable: Children's Congenital Cardiac Services in England: Service Standards: March 2010 – Terminology updated February 2011

<sup>&</sup>lt;sup>26</sup> HSCB: Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the population of Northern Ireland – Identification of a Preferred Option April 2013

identified, including DHSSPS Paediatric Surgery and ENT service standards, which were published in 2010. In addition, a number of recent reports from the Regulation and Quality Improvement Authority have made recommendations on neonatal and general paediatric services which are pertinent to this Review.

# Section C: Prevalence and Need

## **Overview**

- 4.1 Most children and young people in Northern Ireland can expect to live longer, healthier lives than ever before. In the 2011/12 Health Survey for Northern Ireland<sup>27</sup>, parents were asked about the health of their children. The majority (93%) of parents reported that their children's health was generally good or very good.
- 4.2 While most children spend most of their childhood without much contact with paediatric services, it is worth noting that the Health and Social Care Board (HSCB) estimate that around 1/4 of all children will be admitted to hospital during their first year of life. There is also a significant number of children who have long term conditions; for example, asthma, epilepsy or diabetes that require ongoing input from paediatric services. In addition, technological and clinical advances mean that an increasing number of children with serious and complex conditions survive infancy and early childhood and need expert input from paediatric services to ensure they lead as long and full a life as possible.

## Demography

4.3 The number of persons aged 0-17 living in Northern Ireland has decreased by 4.6%, from 451,514 in the 2001 Census to 430,7632 in the 2011 Census (Table 1).

<sup>&</sup>lt;sup>27</sup> The Health Survey for Northern Ireland NISRA

Table 1: NI Population (aged 0-17 years); 2001 – 2011 (source NISRA)

Trust	2001	2011	% change
Belfast	84,583	74,162	-14.1%
Northern	111,478	109,320	-2.0%
South Eastern	83,118	80,986	-2.6%
Southern	89,344	91,941	2.8%
Western	82,991	74,354	-11.6%
NI	451,514	430,763	-4.6%

4.4 While the total childhood population has decreased, the population in the 0-4 age group has increased by 7.4% over this same time period. This is important as the 0-4 age group are much more likely to use paediatric services, compared to older children and young people.

Trust	2001	2011	Change
Belfast	20,986	22097	5.0%
Northern	28,971	31135	7.0%
South Eastern	21,142	23159	8.7%
Southern	23,018	27546	16.4%
Western	21,121	20445	-3.3%
NI	115,238	124382	7.4%

Table 2: NI HSC Trust Populations (aged 0-4 years); 2001 – 2011

4.5 This increase in the 0-4 population has been driven by an increase in births over the same period. In 2011, there were 25,273 births registered in Northern Ireland. This compares to a record low in 2002 where there were 21,385 births. Since then the number of births increased year on year, until 2008 from when it has been relatively stable. However, this is still well below the all time peak seen in 1964 of 34,345 births as shown in Figure 1 below.





#### Care for new born babies

4.6 The increasing births means there are more babies being cared for in maternity wards, neonatal units and in the community. It is not just the increase in the number of babies that presents challenges. Other factors such as increasing maternal age, maternal obesity, and an increase in births to mothers who do not speak English as a first language and advances in medical treatments also place demands on neonatal and paediatric services.

- 4.7 in addition to an increasing number of births there has also been an increase in the number of multiple births. In 2011, 1.7% of births or around 1 delivery in every 60 resulted in a multiple birth - the highest level ever recorded in Northern Ireland. In the past the incidence of twins was around 1 in 80 maternities. Twins and other multiple births are more likely to need neonatal care or input from paediatricians in the newborn period.
- 4.8 Advances in neonatal care mean that with the help of specialist teams, more babies born very prematurely or who have severe congenital abnormalities now survive the neonatal period. In many cases babies spend long periods receiving neonatal care before discharge.
- 4.9 Preterm birth is associated with increased rates of neonatal mortality and long term morbidities such as respiratory problems, learning difficulties, cerebral palsy, and behavioural problems that are highest in the most immature. This is an important issue as more babies are now surviving preterm births.<sup>28</sup>

#### Lifestyle and service impact

#### Breastfeeding

4.10 Breastfeeding rates in Northern Ireland are among the lowest in the world. In Northern Ireland, 64% women breastfeed at birth however this declines significantly in the weeks following birth; from 64% at birth to 46% at one week, 33% at six weeks and 15% at six months (Infant Feeding Survey 2010). Breastfeeding rates are strongly associated with deprivation status: mothers living in the 20% least deprived wards in Northern Ireland are on average twice (1.9 times) as likely to breastfeed at birth as those mothers living in the 20% most deprived wards (CHS).

<sup>&</sup>lt;sup>28</sup> Field D, Draper ES, Fenton A, Papiernik E, Zeitlin J, Blondel B, et al. Rates of very preterm birth in Europe and neonatal mortality rates. Arch Dis Child Fetal Neonatal Ed2009;94:F253-6

# Table 3 Proportion of mothers' breastfeeding on discharge fromhospital

Area	2009	2010	2011
Northern Ireland	44.3%	45.8%	44.6%
20% Most Deprived Areas	30.5%	32.5%	29.8%
Source: PSAB, DHSSPS, Child H	lealth System		

- 4.11 Breastfeeding is associated with reduced incidence of respiratory infections, gastroenteritis and ear infections. Respiratory infections and gastroenteritis are the most common reason for admission to hospital among babies in their first year of life. Northern Ireland's low breast feeding rates are likely to be contributing to high admission rates for these conditions in babies.
- 4.12 A large study carried out in the UK suggests that 53% of admissions for diarrhoea and 27% admissions for lower respiratory tract infections (LRTI) could be prevented if babies were breastfed exclusively for the first 6 months of life. Even partial breastfeeding would have benefits and it is estimated that 30% of diarrhoea admissions and 25% of LRTI infections could be prevented if babies were partially breastfed<sup>29</sup>.

#### Childhood obesity

4.13 Based on 2010/11 data obtained from the Child Health System, almost a quarter (23%) of children in Primary 1 were overweight (17%) or obese (6%). In Year 8 the proportion of overweight and obese children was higher at 29%, with 22% overweight and 7% obese.

<sup>&</sup>lt;sup>29</sup> <u>Ouigley M.A., Kelly Y.J., Sacker A.S. (2007) Breastfeeding and Hospitalization for Diarrheal</u> and Respiratory Infection in the United Kingdom Millennium Cohort Study. Paediatrics; 119; <u>e837- e842</u>

# Smoking

- 4.14 Child and adolescent smoking causes serious risks to health. The earlier children become regular smokers and persist in the habit as adults, the greater the risk of developing lung cancer or heart disease. Early uptake of smoking is associated with:
  - subsequent heavier smoking;
  - higher levels of dependency;
  - a lower chance of quitting;
  - higher mortality.
- 4.15 According to the Young Person's Behaviour and Attitude Survey 2010<sup>30</sup> by the age of 13, 62% of children in Northern Ireland have smoked tobacco, with a quarter of this group smoking every day.

# Drugs and alcohol

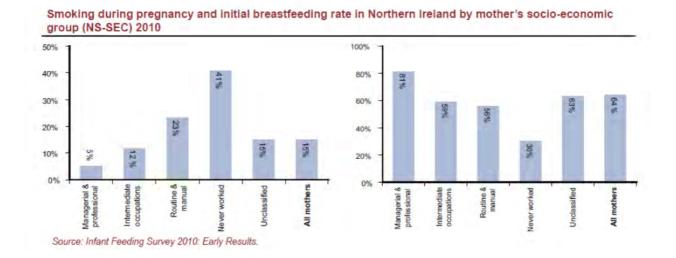
4.16 The Young Person's Behaviour and Attitude Survey 2010 revealed that 46% of pupils aged 11 to 16 years had consumed alcohol and 23% of pupils had been drunk on at least one occasion. A quarter (25%) of respondents had been offered drugs (including solvents) on at least one occasion. In total, 15% of respondents had taken drugs on at least one occasion, while 11% had taken drugs in the last year and 7% in the last month.

## Health inequalities and deprivation

- 4.17 Populations from deprived areas in Northern Ireland experience:
  - Lower life expectancy than the Northern Ireland average: for 2008-10, male life expectancy in the 20% most deprived areas was 72.6 years compared with the Northern Ireland average 77.1 years while female life expectancy in the 20% most deprived areas was 78.9 years compared with the Northern Ireland average of 81.5 years;
  - 33% higher rates of emergency admission to hospital;
  - 72% higher rates of respiratory mortality;

<sup>&</sup>lt;sup>30</sup> Young Person's Behaviour and Attitude Survey 2010 NISRA www.nisra.gov.uk

- 59% higher rates of lung cancer;
- 82% higher rates of suicide;
- Self harm admissions at more than twice (115% higher) the Northern Ireland average;
- 55% higher rates of smoking related deaths;
- 124% higher rates of alcohol related deaths.
- 4.18 Children from areas with higher deprivation have poorer health than those from more affluent areas. Low breastfeeding rates, high levels of maternal smoking, and low birth weight are all more common in areas with the highest relative deprivation. These factors contribute to poorer health among children and influence the need for paediatric services.



# Figure 2

4.19 Children living in more deprived areas of Northern Ireland are more likely to have an unplanned (emergency) admission to hospital. Unplanned hospital admission rates among 0-15 year olds are more than 30% higher in the most deprived one fifth wards compared to the least deprived one fifth wards.

#### Common causes of morbidity and mortality

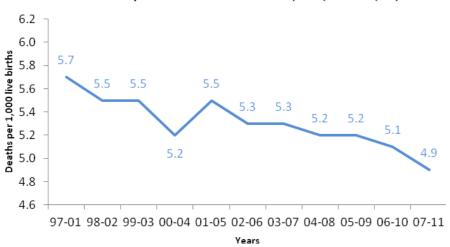
4.20 In 2011, 173 deaths occurred in the age range 0-17 years, of which 64% (110) occurred among children aged under one. The most common causes were disorders related to prematurity and low birth weight.

Number of deaths	Death rate per 100,000 population
110	430
18	18
7	6
10	8
28	38
	110 18 7 10

#### Table 4 Deaths in 0-17 year olds 2011 (Source NISRA)

4.21 In 2011 there were 110 infant deaths (deaths of children aged under one). Most of these deaths were related to congenital abnormalities or prematurity. Other common causes of death in the first year of life include respiratory conditions in the newborn. Infant mortality is recorded using a 5 year rolling figure. The graph below shows a general decline in infant mortality from 5.7 deaths per 1000 live births in 1997/2001 to 4.9 in 2007/2011. In 2011, while just at the commencement of the next 5 year cycle, it is known that the rate was 4.3 in 2011; the lowest ever recorded.

# Figure 3



#### Infant Mortality Rates in Northern Ireland (1997/01-2007/11)

#### Cancer

- 4.22 On average around 60 children aged 0-17 are diagnosed with cancer each year. Treatments are improving and around 80% children diagnosed with cancer now survive. There are around 10 deaths from cancer among 0-17 year olds each year in Northern Ireland (Source NI Cancer Registry).
- 4.23 The figures above relate to new diagnoses of cancer. This is different to the number of children and young people who are living with a diagnosis of cancer. At the end of 2010 there were 441 children (aged 0-17) living who had a diagnosis of cancer at some point.
- 4.24 The most common type of cancers in the 0-17 age group are Leukaemia, Brain, Lymphoma and kidney cancer.

#### **Unintentional injury**

4.25 Unintentional injury, defined as injury that is not caused on purpose and there is no intent to harm, is one of the leading causes of morbidity and mortality in childhood. Unintentional injury is one of the most common reasons children and young people present to hospital services. They range from minor cuts, bruises and fractures to serious life threatening trauma. Certain groups of

children experience injuries more often than others, including boys and those living in deprived areas or from a lower socio-economic background. Child injuries have some of the steepest social gradients for deaths compared with other causes.

#### Non-accidental injury

4.26 Non-accidental injury includes injuries deliberately inflicted on the child by themselves or others. This includes deliberate harm to children which raise safeguarding concerns. At present it is not possible to produce figures relating to the number of children presenting to Emergency Departments (EDs) as a result of non-accidental injuries as information is collected under referrals under the safe-guarding policies. Deliberate self-harm is an increasing concern and figures for those children presenting to ED are available. While numbers in the under15 age group are small, there are around 280 in the 15-19 year age group attending EDs due to deliberate self-harm. This figure represents the second highest in any age group as the table below sets out.

Table 5 Number of Deliberate Self Harm presentations to EmergencyCare Departments by Age Group (April 2012 – March 2013) Source:DHSSPS Information and Analysis Directorate

	BHSCT	SEHSCT	NHSCT	SHSCT	WHSCT	N Ireland
<15 years	43	42	26	25	21	157
15 – 19 years	353	303	177	163	200	1,196
20 – 24 years	460	225	227	224	244	1,380
25 – 29 years	308	152	161	195	180	996
30 – 34 years	234	149	137	102	163	785
35 – 39 years	205	144	159	142	172	822
40 – 44 years	187	157	173	159	169	845
45 – 49 years	234	179	169	146	129	857
50 – 54 years	168	123	92	120	95	598
55 – 59 years	103	68	46	74	60	351
60 – 64 years	29	33	26	26	26	140
65+ years	36	46	22	21	26	151
Unknown	1	0	0	0	0	1
All Ages	2,361	1,621	1,415	1,397	1,485	8,279

#### Acute childhood illnesses

- 4.27 Successful childhood vaccination programmes mean that diseases such as diptheria, tetanus and measles are now extremely rare among children in Northern Ireland. However, infection is still the most common reason for attendance at an ED or admission to hospital in the 0-17 age group.
- 4.28 The vast majority of these infections are upper respiratory tract infections. Meningococcal disease and other life threatening infections account for a relatively small proportion of hospital admissions. In 2011 there were 60

cases of meningococcal disease notified to the Public Health Agency. The majority of these cases were in the 0-17 age group.

#### Acute surgical conditions

4.29 Children can present with conditions that require assessment and treatment by a surgeon. The most common acute surgical presentation requiring an operation is appendicitis. There are some surgical conditions which mainly present in younger children. These include intusussception (a condition where one piece of the bowel slides into the next and the bowel folds over itself). For every child who needs an operation many more will be admitted with abdominal pain for observation and investigation to rule out an acute surgical problem.

#### Long term conditions

- 4.30 Parents responding to the Northern Ireland Health Survey were asked if their children had a longstanding illness. Thirteen percent of children were described by their parent as having a long-standing illness, with asthma being the most frequently mentioned. Of those children who had a long-standing illness, around half (48%) had an illness that limited their activities in some way.
- 4.31 Having a long term condition can have a major impact on children's lives that goes beyond those associated with symptoms and medical management. Long term conditions can result in periods of absence from school, not being able to take part in activities with peers and make a child feel different.

#### Asthma

4.32 Asthma is the most commonly diagnosed long term disease among children. Around 1 in 7 children (14%) in Northern Ireland have been diagnosed as having asthma. The severity of asthma varies widely. At the milder end of the spectrum are children who experience mild symptoms that are managed easily by their GP. However, children whose asthma is more severe often require relatively frequent admission to hospital with associated school absence.

#### Epilepsy

4.33 There are around 2,000 children in Northern Ireland with epilepsy. Epilepsy is a common and diverse set of long term neurological disorders characterized by seizures. Epilepsy can have a huge impact on children's lives and good seizure control is crucial to allow children to lead normal lives. Seizures can have a negative impact on children's cognitive development and good epilepsy management is essential to minimise this.

#### Diabetes

4.34 Around 1,000 children in Northern Ireland have diabetes. The vast majority have type one diabetes which requires regular insulin injections. This type of diabetes is not preventable and is not related to obesity. Developments in management, including the use of insulin pumps, mean that these children can have better control of their diabetes.

#### Rare diseases

- 4.35 In response to the 2009 European Council Recommendation calling on Member States to establish and implement a national plan or strategy for rare diseases, a UK Plan for Rare Diseases will be developed and published by the end of 2013. This will be adopted by each country within the UK as the basis for implementation within their own jurisdictions. It is likely that the Rare Disease Plan will include issues which are known to be of importance to those suffering from rare diseases and for their families, such as how to tackle often protracted diagnosis experienced by patients and proposals on improving the current experience of patients and their families.
- 4.36 It is expected that specifically for Northern Ireland there will be clear recognition of the benefits of cooperation with rest of the UK and the Republic of Ireland. This is significant because, by the very nature of rare diseases, the number of people suffering from them is very small and rare diseases, as with

other diseases, do not respect borders. The relatively small size of the population in Northern Ireland means that clinicians might only see a small number of children with each rare condition during their career. Children with these rare conditions may need access to specialist centres outside Northern Ireland as well as ongoing care from local paediatric services to ensure they receive the best treatment.

#### **Children with Complex Physical Needs**

- 4.37 Advances in the management of children suffering from a range of life limiting problems mean that more children with these complex problems now survive longer. However, in some cases they have very complex issues including breathing difficulties that need to be managed.
- 4.38 There are around 500 children in Northern Ireland with complex healthcare needs. At the most complex end of the spectrum there are around 25 children living at home who are ventilator dependent (on life support machines). A further 120 children living at home require some sort of help with their breathing.
- 4.39 Putting in place both the technical and staffing arrangements to make sure children with complex needs can be looked after at home or as close to home as possible requires detailed planning and significant support from the Health and Social Care System.

#### **Summary**

4.40 This section outlines the children's population and the impact that lifestyle, health inequalities and deprivation has on the use of Northern Ireland's health and social care services. The main causes of ill health and death in childhood are prematurity, congenital conditions, acute medical and surgical conditions, long term conditions such as asthma, epilepsy, diabetes and the significant impact of children with complex needs.

# **Section D: Current Service Provision**

# **Current Configuration**

- 5.1 The vast majority of health services for children and young people are delivered in primary and community care by general practitioners (25% of all GP consultations relate to children<sup>31</sup>), community pharmacists, dentists, optometrists and community teams, for example, nurses, health visitors, allied health professionals and social workers. In addition, the GP Out of Hours (GP OOH) services deliver acute paediatric care.
- 5.2 Acute paediatric services delivered by HSC Trusts mainly relate to:-
  - <u>emergency/urgent care</u> as delivered through Emergency
     Departments, Urgent Care and Treatment Centres, and Minor Injuries
     Units;
  - <u>paediatric medicine</u> both unscheduled and planned care, for example, via rapid response units, inpatient, outpatient services, intensive care units and community teams, especially for long term conditions;
  - *paediatric surgery* both unscheduled and planned, for example, inpatient, day case, and outpatient services.
- 5.3 All HSC Trusts deliver acute paediatric services. These services are mainly located within the current hospital configuration although some other paediatric services are delivered in other settings, for example in Community Care and Treatment Centres or as part of a community team, or specialist paediatric outreach service delivered by the main hospital into local settings.

<sup>&</sup>lt;sup>31</sup> Royal College of General Practitioners

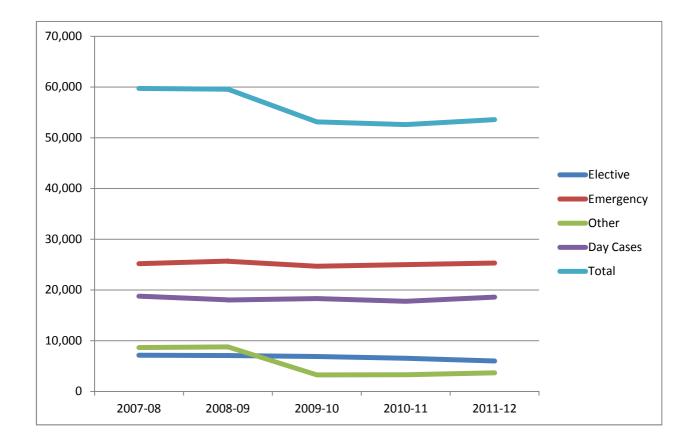
#### Age limits for Paediatric Medical and Surgical Services

5.4 There is variability of age limits for paediatric admissions to hospitals in Northern Ireland. The Royal Belfast Hospital for Sick Children (RBHSC) admits children up to 13 years onto the paediatric medical/surgical wards/outpatients and up to 14 yrs from their emergency department. Most district general hospital (DGH) paediatric units admit up to the 16<sup>th</sup> birthday. Such variability makes access and the coordination of care more difficult across HSC Trusts but also means that for many children and young people the only option open to them is inpatient admission on an adult ward. It should, however, be noted that sometimes clinical conditions necessitate flexibility in age limits. This is especially the case for some complex, and life limiting, conditions where it may be in the best interests of the child for the designated team to look after the patient for many years up to and beyond their 18<sup>th</sup> birthday.

#### Inpatients and day cases

- 5.5 As we have seen from Section C, many factors influence demand this includes demography, population distribution, birth rates, deprivation, and the epidemiology of disease, for example, seasonal variation with an increase in acute respiratory conditions in winter months.
- 5.6 Over the last five years, the pattern of service provision has changed, with a decrease in the number of emergency and planned hospital admissions.

# Figure 4: Admissions to HSC Hospitals in Northern Ireland under the Acute Programme of Care where the patient was aged 0-17 years, in each of the last 5 years



- 5.7 There were nearly 54,000 inpatient and day case admissions between 0–17 years, representing 10.2% of all admissions to hospital under the acute programme of care. The largest category was general paediatric medicine representing 22,413 admissions (41%). These were mainly inpatient emergency admissions.
- 5.8 ENT was the next highest category (6,073) of admission to hospital with 56% of these cases being undertaken as day case surgery.
- 5.9 The next largest category is a general category with 5,445 cases; mostly a primary diagnosis of dental decay.
- 5.10 Inpatient paediatric services are provided at District General Hospitals (DGHs): Antrim Area Hospital; Altnagelvin; Causeway; Craigavon Area Hospital; Daisy Hill Hospital; South West Acute Hospital; and the Ulster Hospital. The Royal Belfast Hospital for Sick Children (RBHSC) is Northern

Ireland's dedicated children's hospital. It provides DGH services for its local population as well as regional (tertiary) services including paediatric intensive care, specialist surgery, cancer treatment, cardiology, and other medical specialities.

5.11 In addition to the above, there is a range of services which are of a highly specialist type which cannot always be delivered locally. This is usually because of the relatively low volume of patients and specialist skills required to secure a high quality, sustainable service, together with the need to have, on the same site, other highly specialist services. Such paediatric services are usually for rarer conditions such as for liver and bone disease and are mainly delivered in the Belfast HSC Trust or at national level within certain UK centres.

# Table 6: Six most frequent reasons for elective admission to hospital 0-17 years (including day cases) 2011/12

Diagnosis	No of	% of admissions
	Admissions	
Dental caries	5,994	24.4%
Non-suppurative otitis media	1,338	5.4%
(middle ear infection)		
Chronic tonsils/adenoids	1,315	5.3%
Acute tonsillitis	1,061	4.3%
Chronic renal failure	473	1.9%
Lymphoid leukaemia	441	1.8%

#### **Attendances at Emergency Departments**

- 5.12 There are around 145,000 Emergency Department (ED) attendances each year by children under 16. This is 20% of total attendances at Emergency Departments.
- 5.13 The main reasons for attendance at EDs, usually by self -referral or GP referral, relate to acute infection or injury. By way of example, the RBHSC has analysed its figures for the 10 main reasons for attendance at its ED, which represent approximately 35% of all ED attendances in 2011/12 at RBHSC.

Diagnosis	Total		0-1yrs	1-2yrs	2-3yrs	3-4yrs
Upper resp.		2,459	50	725	654	345
infection						
Gastroenteritis		1,975	25	353	560	295
Head injury		1,944	11	175	317	232
Acute tonsilitis		1,429	0	251	400	237
Acute bronchiolitis		1,303	349	735	46	3
Lr Respiratory tract		1,270	14	246	283	185
infection						
Soft Tissue Injury		1,025	0	15	49	86
Wheeze		1,016	1	255	307	163
Abdominal pain		768	2	10	9	23
Viral infection		743	12	190	149	88

# Table 7: Ten most frequent reasons for Attendance RBHSC Emergency Department 2011/12

- 5.14 Most major acute hospitals have dedicated resuscitation areas within their ED for the management of the acutely ill child. Some also have separate waiting or treatment areas for children.
- 5.15 Some EDs are co-located with out of hours services, which allows triage and referral to those services.
- 5.16 Some hospitals in Northern Ireland operate ambulatory/short-stay/rapid response units to allow urgent diagnostic tests, and expert paediatric opinion, or treatment to reduce the need for admission. Some are on the same site as in-patient units, but there are also stand alone units such as Mid Ulster and Whiteabbey which operate 9am-5pm on Monday to Friday. Tyrone County Hospital has an Urgent Care and Treatment Centre.

#### **Emergency Admissions to Hospital**

5.17 In 2011/12 the most frequently recorded primary diagnosis for emergency admission for 0-17 year olds was viral infection of unspecified site representing 1,535 admissions (7.3%). The top 6 causes are listed below. Of

these six, acute broncholitis had the longest average length of stay at 2.6 days followed by acute lower respiratory infection at 2.1 days.

# Table 8: Most Frequently Recorded Primary Diagnosis for Patients aged0 -17 years Treated Non-Electively under Paediatric Specialties in2011/12

Description	No. of admissions	% of Admissions	Av. Length of stay ( days)
Viral infection of unspecified site	1535	7.3%	1.1
Acute upper respiratory infection of multiple and unspecified sites	1,377	6.6%	1.0
Acute Bronchiolitis	1,252	6.0%	2.6
Viral and other specified intestinal infections	1,177	5.6%	1.1
Acute Tonsillitis	861	4.1%	1.0
Unspecified acute lower respiratory infection	794	3.8%	2.1

## **HSC Capacity in Paediatrics**

5.18 The capacity of a hospital relates to its ability to cater for the needs of its local community and to deliver high quality, safe services which are both effective and efficient. Therefore, hospital capacity relates not only to the number of beds (i.e. physical environment) but also to the availability of other resources such as imaging services, theatres, and laboratory services. But having sufficient bed capacity is of little benefit if there is not the human resource to deliver high quality care. This includes, for example, skilled and competent practitioners such as doctors, nurses, allied health professionals and administrative staff.

5.19 Table 9 below provides an overview of the paediatric bed capacity within hospitals in Northern Ireland. Ambulatory beds are usually used for the acute management of patients as part of a rapid response to need, for example, in the management of acute infection, feeding difficulties or diagnostic procedures undertaken. The beds are usually only open during normal working hours and may not be available at weekends.

Table 9: Designated Beds (Paediatric Medicine and Surgery) & Ambulatory Beds at November 2012 (excludes neonatal, day case and intensive care). Beds are used flexibly depending on service pressures and case mix) (Source: - HSC Trusts – Scoping exercise November 2012)

Trust No. of Inpatient designated Beds/Cots (medical& surgical)		No of Ambulatory beds	
Western	47	4	
Southern	45	5	
South Eastern	51	7	
Belfast	76 plus 15 in Musgrave Park Hospital plus 18 Ophthalmology/ENTin Royal Victoria Hospital	0	
Northern	39	4	
Total	273	20	

5.20 The occupancy<sup>32</sup> level of available beds is also important. For paediatric (medical) admissions in 2011/12 the occupancy level is noted to be variable in Northern Ireland with the highest occupancy level<sup>33</sup> being in the Ulster Hospital (78.9%) closely followed by Antrim Area Hospital (75.5%). The lowest level of occupancy is in the Western Trust in the then Erne Hospital at 48.7%.

<sup>&</sup>lt;sup>32</sup> The average occupancy level is defined as the average number of available and occupied beds during the year in wards that are open overnight, measured at midnight. Hospitals may also have a number of beds in wards that are open during the day. Beds reserved for day care admissions or regular day admission are not included.

<sup>&</sup>lt;sup>33</sup> Source: Hospital inpatient System and KHO3a; paediatrics (specialty 420) – 2011/12

#### Paediatric Intensive Care Unit (PICU)

5.21 There is one paediatric intensive care unit in Northern Ireland located in the RBHSC. This admits children up to the age of 13 years. 50% of PICU bed days are used by the under aged one population and the 0-4 age group account for 80% of bed usage. In 2012, the HSC Board agreed additional funding to provide more capacity in the regional paediatric intensive care unit (PICU) and improve the regional paediatric transport and retrieval system. Overall this investment will secure better services for the most critically ill children and adolescents.

## **Neonatal Care**

- 5.22 Each year in Northern Ireland about 2000 babies<sup>34</sup> will need extra care and will be admitted to a neonatal unit. Most of these babies will need intensive or high dependency care. High staff/patient ratios, specialised equipment and treatment make neonatal services a high cost, relatively low volume, service. The neonatal service is inextricably linked to consultant-led obstetric services, as women of higher risk are delivered in an obstetric unit while women of lower risk, are encouraged to deliver their baby either in a midwife-led unit or at home.
- 5.23 Specialist neonatal services are provided in acute hospitals. The care for each baby can be described in three levels:-
  - <u>Level 1</u>- *Neonatal Intensive care* for babies with the most complex problems who require constant supervision and monitoring and usually mechanical ventilation;
  - <u>Level -2</u>- *High dependency care* for babies who need constant monitoring, for example receiving help with their breathing or having intravenous feeding; and

<sup>&</sup>lt;sup>34</sup> Neonatal Intensive Care Outcomes research and Evaluation (NICORE)

- <u>Level 3</u>- *Special care* for babies who could not reasonably be looked after at home by their mother; for example, because they need monitoring of their heart rate or breathing, or are being fed through a tube or are receiving treatment for jaundice. Special care which occurs alongside the mother is often called "transitional care" but takes place outside of a neonatal unit, in a ward setting.
- 5.24 The following table 10 shows the location and type of neonatal cots in Northern Ireland.

Unit	Level 1 cots (ICU)	Level 2 Cots (HDU)	Level 3 cots (SpC)	Total	Consultant – led Obstetric Service
RJMS***	9	7	15	31	Yes
Antrim**	4	2	10	16	Yes
Ulster**	2	2	9	13	Yes
Craigavon**	3	4	9	16	Yes
Altnagelvin**	3	6	9	18	Yes
Daisy Hill*	0	0.25	5.75	6	Yes
SWAH*	0	0	6	6	Yes
Total	21	21.25	67.75	106	

#### Table 10: Location of neonatal cots in Northern Ireland

\*\*\*Regional Unit – provides neonatal care across all levels in addition to tertiary services

\*\* Area units provide neonatal intensive care, high dependency care (HDU) and special care

\*Provide special care only (Daisy Hill has one cot part funded for level 2)

5.25 A number of recommendations from the Independent Review of Incidents of Pseudomonas Aeruginosa in Neonatal Units in Northern Ireland (2012) are being implemented at HSC Trust and regional levels to improve care, transport and reduce the risk of infection.

# **Outpatient Clinics**

5.26 Outpatient clinics are usually hospital based and led by consultant paediatricians and surgeons working in partnership with a range of professionals. In addition, there are a number of clinics delivered as an outreach from RBHSC and other hospitals to local communities.

- 5.27 All hospitals that have inpatient paediatric units run general medical outpatient clinics, and some medical outpatient clinics are also run in other hospitals or community settings. A range of dedicated specialist clinics are also available. The most common are for asthma, diabetes and epilepsy.
- 5.28 HSC Trusts provide either local paediatric surgical outpatient clinics or alternatively refer children to the regional centre in the RBHSC. There are additional specialist surgical services provided locally such as ENT and dental outpatient clinics.
- 5.29 Hospitals with neonatal ICU cots have dedicated outpatient clinics for neonates to provide follow up care for babies that have been cared for in the neonatal unit.

#### **Regional and Supra-regional Specialities**

- 5.30 A range of highly specialist services are only available in RBHSC. Work has been ongoing to identify and manage some regional specialities, which are considered to be vulnerable due to the numbers of children or dependence on a small number of specialist staff. Examples of these specialities include cleft palate, cystic fibrosis, specialist neurodisability, endocrinology, gastroenterology, rheumatology, haematology and oncology. There is an action plan in place for all of these areas which is underpinned by additional investment in front line services.
- 5.31 In addition to these, there are a number of other specialities which due to their low volume and highly specialist nature are unlikely ever to be available in Northern Ireland but better outcomes can be achieved through networked approaches either with specialist centres within the UK or in the Republic of Ireland. This includes epilepsy surgery, hepatology (liver), complex neurology, and some nephrology services. A network manager has been appointed in RBHSC to oversee the coordination of specialist services for those children whose services cannot be delivered locally.

#### **Community Services**

- 5.32 There are a range of paediatric services delivered in the community. These services adopt a multi-disciplinary approach including community paediatricians, community nursing teams and other specialist nurses, allied health professionals such as physiotherapists and occupational therapists. They also work closely with others involved in the care of children including social services, health visiting, psychology, mental health services and schools.
- 5.33 Community paediatric services provide care for children with a range of conditions. There are specific clinics for childhood asthma, diabetes, attention deficit hyperactivity disorder, epilepsy, neuro-developmental conditions, autism spectrum disorder, feeding problems, eneurisis (bed wetting), constipation, audiology, eyecare and speech, language and communication services. Also, the overlap with palliative and end of life care services is very important.
- 5.34 Child and Adolescent Mental Health Services (CAMHS) provide services for children and young people who have complex mental health needs and the importance of protocols and links between CAHMS and hospitals provide an essential mechanism for the care and treatment of these patients within an acute hospital setting.
- 5.35 It is also important to recognise the special needs of children and young people with learning disabilities within an acute hospital setting to ensure that their treatment and care is properly managed.
- 5.36 There are a growing number of children living with long-term conditions, and many of these children and families have complex physical, social and behavioural needs.
- 5.37 There are also challenges faced by community paediatricians and other healthcare professionals in the earlier recognition, assessment and management of children who have been subjected to or are at risk of sexual

abuse and domestic violence. The introduction of the new Sexual Assault and Referral Centre, opened in 2013, will require further consideration of the interface between these services and paediatric services.

5.38 Managing demand and capacity continues to be a challenge in community paediatrics, and HSC Trusts have reported a difficulty in recruitment of community paediatricians.

# **Children Living with Complex Physical Needs**

- 5.39 As highlighted in Section C, there are 500 children living with complex needs, as defined by NI Paediatric Nursing Tool<sup>35</sup> which is used throughout Northern Ireland to assess needs not just of the child, but also for the social and emotional assessment of the individual, parents and carers.
- 5.40 For the purposes of this Review only, children living with complex needs in the community are children who have clinical risk associated with their condition, for example, the risk of respiratory arrest due to malfunction of their ventilation support. Whilst the number of children is small, this category of children is growing.
- 5.41 Many children with complex needs will have had their initial inpatient care within RBHSC. Planning for the discharge of patients is extremely important to ensure facilities and arrangements are in place locally to meet the child's complex needs. RBHSC plays a significant role in training of staff and parents in the management of these children, further work is required to develop the "step down" transitional team approach, including sustaining services out of hours and at weekends, and crisis intervention.

## Workforce

5.42 The dedicated workforce within general paediatric services and associated specialities comprises teams of professionals, managers and administrative staff. The workforce can be based solely in an acute hospital setting, or can

<sup>&</sup>lt;sup>35</sup> www.dhsspsni.gov.uk/developing\_services\_to\_children\_july\_2009.pdf

work in both hospital and community settings or be located in the community as part of a team based approach to care.

- 5.43 The following paragraphs relate to the main components of the paediatric workforce, but it is also acknowledged that many other professionals play a key role, such as hospital pharmacists, clinical psychologists, specialist nurses and other consultant medical/surgical/anaesthetic staff. How hospital and community out-of hours rotas are covered are of pivotal importance to the sustainability and quality of a service. The following paragraphs provide information on:
  - Medical staffing levels;
  - Nursing staffing levels; and
  - Allied health professionals.

#### **Medical Staffing**

- 5.44 All HSC consultants and non consultant doctors are employed by HSC Trusts. In addition, there is a range of doctors in training who, as part of their postgraduate training provide HSC services within Northern Ireland hospitals and paediatric community services. There are also doctors who are non consultant career grade doctors, who usually have many years of experience working in various paediatric specialities.
- 5.45 Across the UK there is an increasing tendency for sub specialisation for example in neonatology, and specific conditions such as diabetes, and a shortage of general paediatricians. This, together with new working patterns makes sustaining services and rotas difficult, particularly in smaller units.

#### Nursing

5.46 All acute paediatric wards are staffed by children's nurses. Some Emergency Departments have enough children's nurses to provide 24/7 cover, while others rely on adult nurses with additional training in caring for children. In addition some young people are cared for in adult wards where they are usually cared for by adult nurses trained in a number of critical areas that apply to children, for example, management of fluids in children up to 16yrs, management of Diabetic Ketoacidosis (DKA) and safeguarding. Although there is a high level of skill mix in the community, this needs more development in acute services. The role of advanced children's nurse practitioners is working well across the UK but is less developed locally.

- 5.47 In most instances children's nurses in acute sites are managed separately from those working in the community and although there is evidence of interface, models of full integration have not been introduced in Northern Ireland.
- 5.48 Neonatal units are staffed by nurses from an adult or paediatric background and by midwives. Most nurses working in neonatal units undergo further training to enhance their skills in caring for neonates. The role of enhanced and advanced neonatal nurse practitioners working in neonatal facilities has progressed. The increasing complexity of babies being cared for in neonatal units means training of neonatal nurses to meet future service requirements is essential.

#### Allied Health Professionals (AHPs)

5.49 AHP services are an essential part of a team-based approach to treatment and care. Most are delivered in the community, although they are also provided in hospitals for acutely ill children and young people, including paediatric and neonatal intensive care. Their role includes prescribing specialist wheelchairs and equipment, ensuring a child's home environment meets their functional needs, ensuring a child can access the school curriculum, involvement with diet/nutrition, including management of certain eating disorders, and promoting speech and communication. Implementation of the AHP Strategy for the Allied Health Professions in Northern Ireland 2012-2017 'Improving Health and Well-being Through Positive Partnerships' commenced in January 2013. The Strategy outlines how services can be developed through the diversity and wide ranging nature of the AHP disciplines and their practices which include children's services.

#### **Psychological Interventions and Support**

- 5.50 Psychological interventions are an important aspect of paediatric care. These services are different and separate to mainstream child and adolescent mental health services (CAMHS).
- 5.51 They are usually delivered as part of a team based approach to treatment, care and support for the individual child, siblings, and parents either in the community or as part of service provision in an acute hospital. They are beneficial in helping the acceptance of the condition or disability by the child, parents and family; adherence to treatment and adjustment to life. They are also a significant part of the management of end of life and bereavement care. They can also be particularly important in paediatric and neonatal intensive care and in the management of pain, as well as the management of long term conditions.
- 5.52 There are a number of reported gaps in service provision, including psychological interventions in the management of long term conditions for adolescents. In addition there is a challenge for paediatric, psychology and CAMHS when a child or young person who is admitted onto a paediatric ward with self harm.

#### **Voluntary Sector**

5.53 The voluntary sector plays a very significant role in providing information, professional and peer support to parents, families and individuals, helping them cope with illness and injury.

#### Summary

5.54 Paediatric services have undergone considerable change in the last decade. This section has provided an overview of current demand, capacity, service provision and workforce analysis. Issues relating to the deliverability and sustainability of high quality acute paediatric provision have been highlighted. The case for the development of a strategy for the next ten years is driven by population need, increasing complexity of conditions, the need to maintain recognised standards of good practice and workforce constraints. This includes the increasing tendency for subspecialisation in paediatric and neonatal care and the recognition of interdependency of such services with other specialisms such as anaesthetics and consultant led obstetric care. In addition, it is clear that there are conflicting demands between planned and emergency paediatric care with much of the emergency attendances in Emergency Departments being for children from 0-4 years with acute infections and injuries.

5.55 The next section therefore sets out proposals for to enhance the commissioning and provision of paediatric services development and enhancement over the next ten years.

# Section E: Proposals for Enhancing the Commissioning and Provision of Paediatric Services (2014 to 2024)

# Introduction

- 6.1 As we have seen in preceding sections children are major users of health services both in primary care and in hospitals. The Review Team's work with children, their parents and clinicians in reviewing current services, taken together with rising standards for best practice, has convinced the team of the need for stronger links between community and hospital services, and services within and between hospitals. Children's illness and injury can present differently to adults and this means that health and social care staff need specific skills in managing children. Parents need information about where and when to seek help. Primary and community services need to be developed to support most children who become ill or suffer a minor injury and hospital services should be able to rapidly assess, diagnose and manage children who present with more serious illnesses and injuries.
- 6.2 This section therefore recognises the fundamental place of the primary and community care team in the delivery of care to children with both acute and long term conditions. It emphasis that effective links between maternity, neonatal and paediatric services are vital to improved health outcomes. It then drills down into the following specific areas and makes recommendations for the development and enhancement of service provision:
  - Enhanced primary and community care to improve outcomes and the patient experience;
  - Networked approaches to the delivery of paediatric services;
  - Age appropriate care;
  - Improving access to urgent and emergency treatment and care;
  - Improving the access and quality of General Paediatric Services

- Improving the access and quality of Neonatal Services
- Children with Complex Physical Needs

Throughout this section recommendations are made which, following public consultation, will be reviewed and finalised, and will form the basis for service redesign.

6.3 The following recommendations also reflect the position in 'Transforming Your Care', that the fundamental principle of paediatric care is that services should be delivered as locally as possible, but with access to regional services when needed in order to deliver the best outcomes for children and young people.

# Enhanced primary and community care to improve outcomes and the patient experience

- 6.4 We have already seen in Section D that most paediatric illness or injury is managed in the community with a high proportion of GP consultations and out of hours services dealing with babies and children. Many people seek advice directly from family members, but also access advice from their community pharmacists, health visitors, practice nurses and others.
- 6.5 Improving paediatric services starts with children, parents and carers being partners in care and having the right information and support in the community to manage relatively minor illness or injuries themselves. Parents need to know when, how and who to contact for advice when the child's condition is more serious than they can manage themselves. It has been shown that children with good continuity of care are less likely to attend emergency departments and be admitted to hospital<sup>36</sup>. At all times the children, their parents and families should be given information to allow them to be involved in making decisions about their treatment and care. This reflects the commitment in the Northern Ireland Executive's Programme for Government to ensure that people with a long term condition will be offered

<sup>&</sup>lt;sup>36</sup> Paediatric and Child health Services Literature Review; Public Health, Wales July 2011

access to appropriate education, information and support programmes relevant to their needs, including innovative application of connected health. In addition, alternative models of urgent care will provide for enhanced access to services when needed, especially in areas of high deprivation.

6.6 The Department therefore recommends that:

#### Recommendation 1

Information and support provided for paediatric services should be reviewed and enhanced to ensure that the right information and support is available to children, their parents and families so that they may be actively involved in decisions about treatment and care, including selfmanagement.

- 6.7 Primary care professionals such as GPs, pharmacists, health visitors, school nurses, children's nurses, allied health professionals, social workers and others, are all part of an extended community team. These multidisciplinary professionals can help and support parents and their children to better manage acute conditions, such as minor injuries, feeding problems and constipation, as well as long term conditions, and by promoting general health and wellbeing. This access to advice is especially important for parents of babies and young children aged under 5 years who are some of the most vulnerable in our society, and frequently attend emergency departments, with high rates of hospital admission.
- 6.8 Supporting self management and community treatment and care is not only better for the child, parents and other family members; it may also reduce potentially inappropriate demands on emergency departments, outpatient services and admissions to hospital.
- 6.9 Section C has highlighted the prevalence of some common long-term conditions in Northern Ireland such as asthma, diabetes and epilepsy. While there has been some progress in improving services for these children the Department recognises that further improvements are required to ensure a holistic approach in their care and management from childhood through to

adulthood. Early interventions, self management, treatment, care and support is particularly important for children with long term conditions. Children and young people with complex physical needs particularly benefit from a holistic approach, especially at the interface between hospital and community services and in moving from children to adult services.

- 6.10 As part of the implementation of Transforming Your Care, Integrated Care Partnerships (ICP) are being rolled out across Northern Ireland. These multi-sector collaborative networks enable health and social care providers to come together to respond innovatively to the assessed needs of local communities. ICPs will initially focus on frail elderly and aspects of long term conditions (LTC) for all ages, namely diabetes, stroke care and respiratory conditions. This includes palliative and end of life care in respect of these agreed areas.
  17 ICPs are currently being implemented with the aim of ensuring that service users with those LTCs named above including children receive more effective and efficient care.
- 6.11 The Department believes that children's nurses and specialist nurses should act in partnership with the child and parents. The provision of community multi-professional paediatric teams with skilled children's nurses, and trained support workers working across acute hospital and community sectors providing a more integrated model of service delivery would enhance the care provided to children with complex needs and long term conditions, while reducing pressures on secondary care services.

#### 6.12 The Department therefore recommends that:

#### **Recommendation 2**

The Health and Social Care Board and Public Health Agency should work with GPs and other primary care and community care services to further improve access to primary and community care for children and families for those conditions which are more appropriately managed outside secondary care settings.

- 6.13 As technology continues to improve, this should support care in the community. This will include "near patient testing", telemonitoring and teleconferencing. The Department believes that it is important that children's services make use of these technologies, to manage children in the community linked to specialist hospital advice and support.
- 6.14 In order to ensure that the benefits provided by technological innovation are realised for paediatric services the Department recommends that:

The needs of children as well as adults should be recognised in developing services for people with long term conditions, including at transition to adulthood, and supported by improvements in connected health technologies.

#### **Networked Approaches to the Delivery of Paediatric Services**

6.15 Northern Ireland, along with other UK countries has highlighted the benefits of networked approaches to the delivery of health services. These networks, which are usually designated clinical networks (for example, for cancer), operate on a regional basis. The development of a regional paediatric network offers the best opportunity to deliver paediatric services in accordance with the evidence of best practice and in line with "Transforming Your Care" philosophy of "locally where possible - specialist where necessary". It will also help to ensure that children living across Northern Ireland have equity of access to high quality paediatric services. It will be about a whole systems approach to change management for paediatric services provision. For children, a dedicated paediatric network would offer the opportunity to bring together a range of health and social care professionals with specialist expertise, standardising care and access across traditional HSC boundaries. The visible leadership provided by the network combined with a clear focus on outcomes will be essential elements in driving change.

- 6.16 The Department believes that to deliver this vision, the network should be constituted as an operational network, similar in role and function to the Critical Care Network for Northern Ireland (CCaNNI). This would help to ensure that paediatric resources, for example inpatient capacity, are used to maximum effect. The development of an operational network would also help to ensure that children from across Northern Ireland have equitable access to the tertiary paediatric services based in Belfast.
- 6.17 To promote any change in service provision effective commissioning is a key requirement. A regional paediatric network involving a range of commissioners and practitioners would enable staff to manage patients across traditional HSC Trust boundaries. This may mean that while all paediatric services may not be available at every hospital site all children will have access to a range of paediatric services as close to home as possible.
- 6.18 Such a network would develop agreed regional clinical policies and protocols to include access to specialised paediatric advice for local clinicians and a generic referral pathway for assessment, diagnosis and follow up which facilitates the integration of care closer to home, where appropriate. The Network should facilitate the sharing of learning and good practice between organisations in relation to the care of children. Taking account of the RQIA baseline assessment of children aged under 18 in adult wards, the Network should work collaboratively with other HSC organisations to ensure sharing of best practice for the care of children in hospital regardless of the location.
- 6.19 A shift towards prevention, early identification and early intervention are well accepted as being important to securing good outcomes for children. These elements need to be further built into core paediatric service provision via the proposed paediatric network. This, for example, would include a generic focus on major public health issues such as smoking, obesity in children and domestic violence, as well as emergency and planned paediatric general medicine, surgery, specialist services and neonatology.

- 6.20 Parents and carers are strong advocates of the work of the voluntary and community services which clearly add significant value to the care of their children. It is important to build on the relationships that have been developed with these sectors and therefore the proposed paediatric network would be expected to work closely with the voluntary and community service providers.
- 6.21 The Department believes that priority should be given by the HSC to the establishment of a regional paediatric network and therefore recommends that:

A regional paediatric operational network should be established to ensure equity of access to high quality services across Northern Ireland. The network would include commissioners, providers, clinicians and patient representatives and should work closely with the voluntary and community sector.

### Age Appropriate Care

- 6.22 Young children, and their parents, have very different needs to those of adolescents. In order to bring clarity to the commissioning and provision of paediatric services for children and young people in Northern Ireland, the Department proposes that there should be a move to a regional approach to "age banding" in order to promote age appropriate care for children and young people from birth up to aged 18 years. In Section D we have seen that the age at which children transfer to adult HSC services is very variable.
- 6.23 The individual child or young person will have their own view on how their clinical care should be coordinated; but if we are to improve outcomes for children and young people it would be desirable to adopt an approach which establishes the following proposed key principles:

*Dignity* and *Respect* – that supports children and young people to make informed choices about their treatment and care (depending on their level of maturity), and their responsibilities regarding their own health;

*Health Improvement* – recognising that there is a need for paediatric services to be proactive in actively encouraging older children and adolescents to adopt healthier lifestyle choices and behaviours;

*Choice and flexibility* – recognising that no one "service" size fits all but that children and young people will be influenced by their level of maturity, clinical condition, and past experiences, and will have their own views on how/where to access services and inpatient facilities;

Accommodation and facilities – to be provided for the clinical needs of children and young people, and to support age appropriate educational, social and recreational activities;

*Educational* – recognising that paediatric services should be delivered in a way that meets clinical need but also minimises disruption to educational activities, where possible;

*Staff training and development* – those providing treatment and care to adolescents should be specifically trained to understand the clinical, social, behavioural and psychological needs of adolescents in order to improve health outcomes;

*Clinical Leadership* –children should have their care clearly coordinated by a team, normally the paediatric team but on occasions care will need to be led by the most appropriate clinical speciality who should have access to paediatric advice.

6.24 The RQIA report (2012)<sup>37</sup> highlighted that in 2009-2010, 3933 children aged under18 were being cared for on adult wards; these were mostly adolescents.

 $<sup>^{37}</sup>$  RQIA Baseline assessment of the care of children < 18 admitted to adult wards in Northern Ireland 2012

Adolescence is a time of great physical, emotional, behavioural, and sexual change. Whilst this is a normal part of transition to adulthood, some of these changes can adversely impact on health and wellbeing of the individual, with a potential for greater risk- taking (for example, substance misuse, joyriding and sexual behaviour) and a change in attitude to long term illness with a greater potential for non compliance with treatment, and poorer engagement with health and social care services.

- 6.25 Some hospitals have tried to facilitate inpatient ward areas for adolescents and child friendly areas for older children on wards, outpatients and in emergency departments. It is clear, from the Review team's discussions with young people, that while adolescents do not want to be treated in a ward/clinic which largely caters for younger children or babies, neither do they want to be treated in a ward/clinic with elderly patients, sometimes more than 60 years their senior.
- 6.26 There may be occasions when there is a clinical reason for a child to be cared for in an adult service. To address the clinical and safeguarding issues for children in an adult in patient setting, HSC Trusts should put in place a system that records these children and ensures paediatric input to their care. For young people aged 16 and 17 clinical need, flexibility and choice will be the main elements for discussion and determination on whether an individual should attend a paediatric or adult service. Staff caring for these young people should be aware of consent and safeguarding issues. Adults aged 18 and over will normally be cared for in an adult service, but in some cases young people over 18, especially those with complex needs or conditions mostly seen in paediatric services, may continue to be cared for by the paediatric services.

Children (from birth up to 16<sup>th</sup> birthday) should usually be cared for by the paediatric team in paediatric settings, and those aged 16-17 years should be managed in age appropriate settings within either paediatric or adult settings.

#### Improving access to urgent and emergency treatment and care

- 6.28 20% of attendances at Northern Ireland's hospital emergency departments are children and young people. While more can be done in the community, there will always be a need for rapid access to high quality acute specialist paediatric opinion, especially for common conditions such as respiratory conditions, infections, and abdominal pain.
- 6.29 The Review proposes that there should be continued progress towards implementation of the General Paediatric Surgery and ENT standards which were published by the DHSSPS in 2010. This is a significant interim step to promote better services for children. Children under the age of 5 years should have emergency surgery undertaken in the Royal Belfast Hospital for Sick Children (RBHSC), unless the child's condition is time critical or the designated consultant general surgeon for general paediatric surgery is able to perform the operation within a time period appropriate to the child's clinical condition. Straightforward elective general paediatric surgery should continue to be delivered outside the regional centre in line with the 2010 standards.
- 6.30 Managing acute demand is a key element of all urgent and emergency care pathways. Models in use elsewhere in the UK have highlighted the benefits of a children's assessment unit (for example, a short stay unit for patients of under 24 hours duration), rapid response clinics or ambulatory units (open at peak times during the day, for example,11am-8pm) and at weekends. Such units facilitate direct referral by the emergency department triage nurses, community paediatric teams, GPs and others, for prompt assessment,

investigation and management of the child. This can often avoid the child needing to attend emergency department or inpatient admission. It also promotes shared care where a patient can be referred back to the local GP or community team with further advice on management, if required.

- 6.31 Should discharge to home not be appropriate for the child then full inpatient admission is arranged, for example, to a paediatric ward, critical care, or to specialist services such as a child or adolescent mental health service. Different types of models can be used to obtain a skilled paediatric opinion in acute hospital settings, including developing paediatric teams which includes skilled nurses and other professionals.
- 6.32 In order to harness the benefits described above the Department recommends that:

### **Recommendation 6**

A paediatric model such as rapid response clinics, or short stay assessment and observation units, should be developed to allow rapid assessment and treatment by a range of skilled professionals, which avoids unnecessary inpatient admission. In addition the community children's nurses' skill set should be further developed to provide them with skills in the rapid assessment and management of children who present with an acute medical problem.

6.33 A child or young person attending a hospital emergency department needs to be seen quickly in an age appropriate setting and by skilled professionals. The skill and competence of staff are of the upmost importance. It is the Department's view that in any emergency department which treats children there should be one person on duty at all times who has advanced life support training (APLS) or equivalent, and one children's nurse or nurse with the RCN recognised paediatric competencies in managing children<sup>38</sup>

<sup>&</sup>lt;sup>38</sup> Maximising Nursing Skills in caring for children in Emergency Departments RCN March 2010

- 6.34 In addition every doctor and nurse who is involved in the care of a child or young person in the emergency department should, as a minimum, be competent in:
  - Recognition of a sick child;
  - Paediatric Basic life support;
  - Pain assessment;
  - Recognition of and response to any concerns about safeguarding; and,
  - Effective communication with children and their families.
- 6.35 There is a small but significant minority of children and young people who present with symptoms and signs that give rise to concern about their safety. This could be because of intentional harm, sexual exploitation and abuse, domestic violence, physical or emotional neglect. Recognising and responding to concerns about safeguarding is an integral part of Northern Ireland's health and social care system, and is particularly relevant for those staff working in emergency and urgent paediatric care. The future integration of Information Communication and Technology (ICT) systems may assist in the earlier identification of children at risk; however, this is no substitute for the continued vigilance of staff, expert skills in earlier identification and intervention, and appropriate management and communication protocols including onward referral to appropriate services, for example, Children's Gateway Teams and the Sexual Assault and Referral Centre.

Children presenting to Emergency Departments should be cared for by staff with appropriate skills including paediatric basic life support and safeguarding training. At all times there should be:

- at least one member of staff trained to advanced paediatric life support standard or equivalent and one children's nurse or nurse with a core set of competencies and skills as set out in the RCN document 'Maximising Nursing Skills in caring for children in Emergency Departments' (March 2010);
- arrangements in place for immediate paediatric input to care; and,
- at least one member of staff who has received appropriate training in the management of child protection and child safeguarding issues.
- 6.37 The aim of providing expert help as soon as possible has to be balanced by the importance of accessible services as close to home as possible. When on-site paediatric services are not available the emergency skills of emergency department staff should be enhanced. This should include the availability of senior emergency department clinicians with skills to distinguish minor from more serious illness, life support and stabilisation skills. Criteria should be in place for seeking paediatric advice from a local paediatric service, and for transfer or admission to emergency departments or paediatric units. HSC Trusts need to manage such risk appropriately, and regularly communicate with the public, Northern Ireland Ambulance Service, GPs and other primary and community practitioners about what services are available in each emergency department.

Emergency Departments that accept children under 16 but which do not have paediatric on-site support, should have senior emergency department clinicians\* with skills to distinguish minor from more serious illness and injury, life support and stabilisation skills available at all times.

\*Associate specialist, staff grade, ST4 or higher, Advanced nurse practitioner or equivalent

- 6.39 A physical environment which separates children and young people from adults should be incorporated into commissioning and redesign of Northern Ireland's major hospitals. Separation from adults will facilitate safe, hygienic and less stressful waiting areas for the child and their family. There should also be at least one treatment cubical which is child friendly and one resuscitation trolley with immediate access to children's resuscitation equipment and algorithms and other relevant protocols including use of IV fluids. Where possible, a dedicated paediatric triage area should be available, especially at peak times which are typically the afternoon and early evenings.
- 6.40 The Department therefore recommends that:

#### **Recommendation 9**

Emergency Departments that accept children under 16 should have a paediatric resuscitation area with immediate access to children's resuscitation equipment and algorithms. Emergency Departments should also have a physical environment which separates children and young people from adults where possible.

#### Improving the Access and Quality of General Paediatric Services

#### General medicine

- 6.41 Paediatric medicine is a branch of medicine (i.e. not surgery) that encompasses the management of clinical conditions in infants, children and adolescents. It has due regard for the child's health and wellbeing, and their biological, psychological, social and educational circumstances. It is a holistic speciality dealing with children as part of their family and social settings. It is a large and diverse field encompassing general paediatric medicine and high technology sub specialities such as paediatric cardiology, neonatology, oncology and neuro-disability, and many more. It includes both elective and emergency paediatric medicine.
- 6.42 General paediatric medicine is the bedrock of this speciality. Common conditions presenting to general paediatric medicine include abdominal pain, infections (for example, respiratory, urinary tract, bowel, and meningitis), the "unwell child", allergies and failure to thrive. It is always delivered as part of a multidisciplinary team approach to include doctors, nurses, support workers, allied health professionals, social workers and pharmacists. Importantly, many voluntary organisations are also part of this team based approach as they will have a range of advice, information and support to assist parents and children to better manage their condition.
- 6.43 As paediatric medicine changes, the boundaries between traditional hospital and community based care has become less well defined. The proposed regional paediatric network will therefore provide the opportunity for enhanced working arrangements across hospital and community services with links to the Neonatal Network and the Integrated Care Partnerships. It is envisaged that within the multi-professional paediatric network, there will be a paediatric medicine sub-group to co-ordinate elective and emergency paediatric medicine.
- 6.44 The competence of staff and the model of care locally provided for children in the field of general paediatric medicine drives the quality of service provision and patient outcomes. Some conditions might be better managed by expert

rapid advice and a short stay assessment and treatment without full overnight in-patient admission. But if a child has to be admitted to hospital the aim is to provide rapid, effective treatment and care within the shortest possible period and discharge the child home safely providing care and support at home, if needed.

6.45 Therefore in line with recognised clinical best practice, the Department recommends that:

#### **Recommendation 10**

Every child who is admitted to a paediatric department should be seen by a paediatric practitioner at ST 4\* or equivalent (including advanced children's nurse practitioner)<sup>39</sup> within four hours of admission and by a consultant within 24 hours of admission.

\*Assessment by St4 or equivalent within 4 hours of admission means that in practical terms there should be a St4 practitioner or higher resident in the hospital.

6.46 Acutely ill children have different needs to those of ill adults. The size of their bodies means that they have a different reaction to illness and injury, sometimes leading to more rapid deterioration in their wellbeing. Physiological early warning systems (PEWS) are tools for the recording of physiological measurements (e.g. pulse, respiratory rate, level of consciousness, temperature etc) and help to determine whether intervention is required. Such systems have international recognition as a key element of safer care with the promotion of earlier intervention in patients who may be deteriorating. The Department recognises that because both children and staff may transfer between different care settings across the region, there is a need for a regional approach. Related work is therefore ongoing by the Public

<sup>&</sup>lt;sup>39</sup> advanced nurse practitioner, staff grade or associate specialist doctor or Doctor in training at ST4 or higher. The RCPCH standard advises that if the most senior person to review the child is St3 or equivalent, consultant review should happen within 12 hours.

Health Agency and HSC Safety Forum, and as part of implementation of the 'NCEPOD<sup>40</sup> report *Are We There Yet*?' which should address this issue.

- 6.47 Children who have been admitted to hospital should have an agreed discharge plan, with clear information provided to parents and young people on their management, any planned follow up and when and how to seek advice if required. This is an essential element of good practice and child protection, and may prevent harm and unnecessary readmission in the future.
- 6.48 The Royal Belfast Hospital for Sick Children (RBHSC) acts as both a general paediatric service for its large local community as well as being the regional centre for specialised services for Northern Ireland. Recent information from the HSC Board has highlighted capacity pressures on some general paediatric wards, particularly in the RBHSC. For example, it is known that in 2011/2012 around 450 patients who required inpatient admission for general paediatric care from the emergency department in RBHSC, had to be transferred to another acute hospital, as no beds were available in RBHSC at the time.
- 6.49 At the same time, district general hospitals have all highlighted difficulties in accessing paediatric beds in RBHSC for children requiring regional specialist services. In order to facilitate a better access to services and for the future planning of paediatric services, a clear distinction between general and specialised paediatric services is needed, especially in the Belfast HSC Trust. This will need to be reviewed as the age limit for paediatric inpatient services is increased in line with recommendation 5.

<sup>&</sup>lt;sup>40</sup> Surgery in Children: Are We There Yet? NCEPOD (2011)

In order to further promote equity of access there should be clearly defined capacity for both specialist paediatric services and general paediatric services in the RBHSC. This is to ensure equity of access to specialist services for children across Northern Ireland and to ensure that children residing in Belfast can access general paediatric services in their local hospital.

#### Specialised Paediatric Services

- 6.51 Specialised paediatric services are usually considered to be regionally, (or nationally), commissioned services. They are often complex services with many associated interdependencies which are described below.
- 6.52 To ensure the safe and effective delivery of accessible services for children with specialised needs requires an integrated approach to service delivery and highly skilled and competent teams of staff to cover the needs of children on a 24/7 basis. These needs will differ but are likely to include access to services such as paediatric intensive care, specialised paediatric anaesthesia, ENT (airway complications) and specialised paediatric surgery.
- 6.53 The Department recognises that there is a range of interdependencies for specialised paediatric areas such as plastic surgery, immunology, urology and oncology. Any centre which provides specialised paediatric services needs to have a sufficient volume of specialised paediatric care to ensure that they can provide comprehensive support services in order to promote the best possible clinical outcome and patient experience. This may require individuals and families to travel to access the regional hospital.
- 6.54 The RBHSC is the regional children's hospital for Northern Ireland. This does not necessarily mean that all services have to be delivered centrally but they

should be coordinated regionally through a networked approach. This approach is currently being supported by the work of the HSC Board and Public Health Agency to coordinate and improve specialised "vulnerable" paediatric services. The Department envisages that, in the future, this work would be subsumed into the proposed regional paediatric network. While commissioners and the proposed network would promote local access, where possible, sometimes it may need to extend its networked arrangements outside of the jurisdiction of Northern Ireland.

6.55 The Department recommends that in order to further strengthen the existing and envisaged commissioning and service delivery arrangements:

#### **Recommendation 12**

The Health and Social Care Board and the Public Health Agency should support formal partnerships with other units in the United Kingdom or Republic of Ireland in order to provide support and sustainability of local service provision where safe and appropriate to do so.

- 6.56 In addition to providing specialised paediatric assessment, diagnosis and treatment, part of the role of a regional centre is to provide access to clinical advice and support, when needed, for other clinicians. This may be required urgently and out of hours or could involve, for example, a planned assessment in a short stay assessment unit with the discharge of the child back to his/her own community. The use of new technologies such as telemedicine may also provide more rapid local support. Clear guidance on how to access specialist advice and support is an essential element of a high quality service.
- 6.57 The Department therefore envisages that the paediatric network should develop agreed regional clinical policies and protocols to include urgent access to specialised paediatric advice for local clinicians, and a generic referral pathway for assessment, diagnosis and follow up which facilities the integration of care closer to home, where appropriate.

## General Paediatric surgery and Paediatric ENT surgery

- 6.58 General paediatric surgery is surgery for common conditions in children and young people such as elective or emergency hernia surgery, orchidpexy for undescended testes, acute abdominal pain including appendicitis, minor trauma and abscesses . ENT surgery for ears, nose and throat includes common procedures such as removal of tonsils and adenoids, and management of acute and chronic ear infections.
- 6.59 As highlighted in Section D, the DHSSPS produced linked standards for both general paediatric surgery and general ENT surgery in 2010. These were based on the Children's Surgical Forum of the Royal College of Surgeons<sup>41</sup>. These standards included as a general principle specialised paediatric surgery and all general surgery for children under 5 years and ENT for children under 6 months should be performed at RBHSC, while older children should be cared for locally. In addition children with long term conditions or other clinical reasons that increase the difficulty of general surgery should have their surgery in RBHSC. Local surgical services should be team based with surgeons and anaesthetists demonstrating skills and experience of children's surgery, and elective inpatient general surgery only taking place on a site where there is inpatient paediatric medical facilities and senior clinical cover, including appropriate resuscitation and airways management.
- 6.60 The standards were for paediatric patients up to their 13<sup>th</sup> birthday. In 2012, the HSC Board reviewed the progress being made in each HSC Trust against these standards. It demonstrated that while some progress has been made, the standards have not been fully implemented. Continued effort needs to be made to implement these standards across all Trusts. As we move forward to implement age appropriate care for children and young people from 0-18 years, further work will be required on these standards.
- 6.61 The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is a long established review. In 2011 it published a report into

<sup>&</sup>lt;sup>41</sup> Children's Surgical Forum, Royal College of Surgeons, 2010. *Ensuring the provision of General Paediatric surgery in the District General Hospital*. London: Royal College of Surgeons England

childrens surgery called 'Are we there yet?' Many of the recommendations were in line with the DHSSPS standards for general surgery and ENT surgery. Commissioners and HSC Trusts are already working to implement the recommendations of the NCEPOD report and the DHSSPS standards.

- 6.62 There is an important interface between the regional and local service. A balanced approach is needed in considering what can be safely delivered closer to home or whether it is better to further centralise services, thus requiring individuals and families to travel further. From the Review team's preliminary interviews with young people and parents, it was gleaned that they are prepared to travel further in order to ensure that the patient has access to the best expertise and care. This does not necessarily mean that all elective general paediatric surgery has to be delivered in Belfast but there is a clear need to work across traditional HSC Trust boundaries.
- 6.63 The proposed Paediatric Network should work with GPs, community dentists, and other members of surgical teams to review certain conditions and develop alternative pathways for the health and wellbeing of the child. For example, the development of alternative options to dental extraction of decayed teeth in young children, the management of glue ear, or the removal of tonsils.
- 6.64 The Department therefore recommends that:

#### **Recommendation 13**

Within the proposed paediatric network there should be a surgical subgroup to support the safe delivery of paediatric surgical services across Northern Ireland in line with the DHSSPS standards for general paediatric surgery.

#### **Improving Access and Quality of Neonatal Services**

6.65 Neonatology is a sub-specialism of paediatrics. It is where highly technical science and equipment come together with expert staff to give the sickest newborn babies the best chances in life. An integral part of this service is the

recognition of the needs of parents and families at a time of great stress, and the importance of compassion, end of life care and bereavement counselling.

- Neonatal care is inexorably linked to high guality maternity care, fetal 6.66 medicine, and paediatric medicine and surgery. Over the last decade there has been extensive documentation on what service delivers best outcomes<sup>42</sup>,<sup>43</sup>,<sup>44</sup>,<sup>45</sup>. Work is ongoing to implement the recommendations of the Review of Pseudomonas Aeruginosa in Neonatal Units<sup>46</sup>. This includes the development of a neonatal network which is an important element of coordination of service delivery and standards.
- 6.67 The Department recommends that in order to enhance the links between neonatology and paediatrics, the neonatal network should be formally linked into the overarching proposed paediatric network. As the network develops further, links should be made with maternity services, fetal medicine and perinatal mental health services.

#### **Recommendation 14**

In establishing the paediatric network the formal relationship between the paediatric network, the neonatal network and Integrated Care Partnerships should be considered in order to establish firm linkages.

6.68 In terms of definition of neonatal care, the HSC should move towards an agreed approach to the terminology used in describing neonatal care units in line with Toolkit for High Quality Neonatal services (2009). Full details are available in that document, but broadly the definitions of neonatal care units are:

<sup>&</sup>lt;sup>42</sup> Department of Health, Toolkit for High Quality Neonatal Services (2009)

<sup>&</sup>lt;sup>43</sup> British Association of Perinatal Medicine( BAPM); *Standards for Hospitals Providing Neonatal Intensive and* high dependency care (2010) and BAPM Categories of Care(2011)

<sup>&</sup>lt;sup>44</sup> Royal College of Obstetricians and Gynaecologists(RCOG), *Standards for Maternity Care report of a Working party ( 2008);* <sup>45</sup> National Institute for Health and Clinical Excellence(NICE), Specialist Neonatal care, Quality Standards QS4

<sup>(2010)</sup> 

<sup>&</sup>lt;sup>46</sup> Interim and Final Report available from Regulation and Quality Improvement Authority (RQIA) www.rgia.org.uk

- Neonatal intensive care unit provides care for babies with the most complex needs. There is a dedicated rota separate from paediatrics. Most networks have one or two neonatal intensive care units;
- Local neonatal unit provides care for babies who need short-term assistance with breathing, intravenous feeding and/or be of low birth weight. The majority of babies over 27 weeks of gestation and 1,000g weight will usually receive their care, including short periods of intensive care, within their Local Neonatal Unit. They will have clinical care provided by staff on a general paediatric care rota;
- Special care unit provides special care for their own local population. Babies receiving special care may need to have their breathing and heart rate monitored, be fed through a tube, supplied with extra oxygen or treated for jaundice. This category also includes babies who are convalescing from more specialist treatment before they can be discharged. In addition, Special Care Units provide a stabilisation facility for babies who need to be transferred to a Neonatal Intensive Care Unit or Local neonatal unit.
- 6. 69 An important element of this will be the requirements for relevant interdependent services at each of the three levels, to include the valuable contribution of community and voluntary sector organisations, and their role in the provision of expert advice and support for parents and families.
- 6.70 The Department therefore recommends that:

The Health and Social Care Board and the Public Health Agency should work with the neonatal network to develop a service specification for the regional neonatal intensive care unit, local neonatal units and special care units to meet the needs of local populations. 6.71 Risk assessment in pregnancy will determine the best location for the delivery of a mother and her baby, in line with the recommendations of the DHSSPS Maternity Strategy (2012). Those babies at the highest risk need to be cared for in the regional neonatal intensive care unit (Royal Jubilee Maternity Hospital) located within the Belfast HSC Trust. This is to ensure that they have access to the highest level of neonatal consultant care and enhanced multi-professional service, including nurses, allied health professionals, social services and pharmacists.

#### 6.72 The Department therefore recommends that:

#### **Recommendation 16**

Babies with the most complex healthcare needs should normally be cared for in the regional intensive care unit, Royal Jubilee Maternity Hospital, including those under 27 weeks gestation and 1,000g at birth in order to ensure that they have access to the highest level of consultant care and associated services.

#### **Children with Complex Physical Needs**

- 6.73 Children with complex physical needs are more likely to require medical treatment and/or intervention if they become acutely unwell. The children themselves, their carers and families, are very often experts in managing the conditions of such children and recognising early on the symptoms and signs that suggest deterioration. Agreed pathways that provide access to appropriate levels of care when these families are concerned are therefore essential as they can prevent unnecessary and/or prolonged admissions to hospital.
- 6.74 Individual management plans for children with complex physical needs and an emergency passport/card should expedite appropriate treatment and care in

hospital and in the community and reduce delays in transfer between hospital and community services. The HSC Board and Trusts working with the paediatric network should therefore progress the work undertaken by the Regional Interagency Implementation Group for children with complex health needs and in particular put in place a "step down" programme of care to facilitate the earlier discharge of these children into their local community. This will ensure a multi-agency approach and assist in the training of staff and an appropriate skill mix together with a physical environment appropriate to the needs of the individual child.

6.75 The Department therefore recommends that:

# **Recommendation 17**

The Health and Social Care Board, Public Health Agency and Health and Social Care Trusts working with the paediatric network should put in place a "step-down" programme of care to facilitate the earlier discharge of children with complex health needs into their local community.

### Summary

- 6.76 The above recommendations focus on key areas, in which actions are required, to sustain and improve the safety and quality of paediatric medicine and surgery in the future.
- 6.77 In view of the consensus that more paediatric care needs to be provided and managed in the community, closer to home for patients, integrated working between primary and community teams and hospitals becomes even more pivotal in improving outcomes and the patient experience.
- 6.78 The recognition of the importance of age appropriate care, and the need to move into line with standard practice in other UK paediatric units, means that

integrated working within and between organisations is essential to enable delivery of age appropriate care.

6.79 The establishment of the proposed regional paediatric network and its collaborative working with various other health professionals/organisations, subgroups, commissioning bodies, training regulators and the voluntary sector is central to facilitating change. This partnership working should facilitate improved access and quality of general paediatric medicine, specialised paediatric care, paediatric surgery, neonatal services, Integrated Care Partnerships and services for children with complex physical needs.

#### Outcome

Every child will be treated in the most appropriate setting, with access to appropriate staff according to their needs

# **Section F: Enablers for Change**

7.1 There are a number of key enablers to help support the changes envisaged in this document. Workforce development and training; maximising the HSC skill mix to include the nurse practitioner role; imaging and diagnostic services; ICT support; robust outcomes data; and, financial support are all considered enablers in this context.

#### Workforce development and training

- 7.2 The training provided for doctors, nurses and other health professionals should reflect service needs and changes in service delivery. This is required in order to deliver care as close to home as possible and ensure that the fundamental role of primary and community care services in the delivery of care to children with both acute and long term condition needs is supported by a skilled, confident staff.
- 7.3 GPs are major providers of healthcare for children. It is estimated by the Royal College of General Practitioners (RCGP) that 1 in 4 GP consultations are with children. GP trainees should be facilitated to have placements in an acute paediatric setting where they will gain experience in assessing and managing the acutely ill child. In recognition of the significant element of child health within the GP workload, GPs should include child health and safeguarding in their Continuing Professional Development and their performance appraisal.
- 7.4 Emergency Medicine also has a large child health element, with around 20% of attendances at ED being children. Emergency Medicine doctors should therefore also include 'child health and safeguarding' in their Continuing Professional Development and their appraisal.
- 7.5 In respect of doctors (for example, ENT surgeons, some general surgeons, radiologists and anaesthetists) who mostly care for adults, but also have children as a regular part of their workload, the Department recommends that these doctors should work to the standards for General Paediatric Surgery and ENT Surgery published by DHSSPS in 2010, and include the children's

element of their work in their Continuing Professional Development (CPD) and their appraisal. The CPD may include support from paediatric specialists including training placements, mentoring and joint outreach clinics or surgical sessions.

## Recommendation 18

All medical and dental staff who regularly provide care for children should include child health in their annual appraisal.

- 7.6 With the shift of services to the community as envisaged by TYC, and the development of nurse led services in community and acute settings, the skills of children's nurses will need to be enhanced, including increasing the role and numbers of advanced children's nurse practitioners.
- 7.7 The Department therefore recommends that appropriate workforce planning is implemented, to ensure that staffing levels and competencies can safely provide for the needs of children and adolescent as this will be crucial to the success of the proposals in this in this document.

### **Recommendation 19**

The Department should work with regional medical, nursing and allied health professional training providers to ensure that workforce planning and training reflect service needs for children.

# **Imaging and diagnostics**

7.8 The provision of timely, appropriate diagnostic services is crucial to the care of the acutely ill child. Currently there are paediatric trained radiologists in district general hospital settings who undertake paediatric work but also carry out adult work. None of these radiologists work exclusively with children. Radiologists in the Royal Belfast Hospital for Sick Children (RBHSC) work exclusively within the paediatric field. It is recognised that the trend in

radiology is increasingly towards subspecialisation and best practice would suggest that all paediatric radiological examinations be reported by paediatric trained radiologists.

- 7.9 Most hospitals in Northern Ireland now have a radiology system allowing images from any hospital to be reviewed in any other hospital opening the way for remote/centralised or shared reporting. A hub and spoke arrangement may therefore be possible which could potentially involve more sharing of paediatric radiology workload. An increased sharing of expertise could also potentially result in better maintenance of skills in district general hospitals. Radiologists could spend some time in the base hospital and some sessions in the RHBSC and consultants based in the RBHSC could undertake sessions regularly in other district general hospitals. This would also ensure training/skills maintenance as well as raise standards.
- 7.10 Out of hours emergency radiology cover continues to prove difficult for some hospitals particularly during periods of leave. The Department therefore suggests that the potential for out of hours cover to be shared on a Province wide basis, with a paediatric radiology on call rota, should be explored by the HSCB.
- 7.11 Overall the potential to re-profile existing working patterns in district general hospitals and in the tertiary centre should be explored to address the interface between the local district general hospitals and the regional centre.

# **Recommendation 20**

The Health and Social Care Board should work with the Health and Social Care Trusts to ensure regional availability of paediatric radiology expertise, including out of hours.

## Information Communication and Technology (ICT)

- 7.12 The 'DHSSPS Information Communication and Technology Strategy' published in 2005 centres on advancing the development of electronic care records, improving electronic care communications, and investing in the technical infrastructure required to underpin these two central themes. Good electronic care record systems are required to support safe and effective care, to share care records where this is required in the course of an individual's care, and to provide data for audit and management purposes. Good electronic care communications facilities are likewise essential to improving safety and productivity in many of the processes involved in delivering care e.g. making referrals, ordering diagnostic tests, receiving results of diagnostic tests, providing the information required to effectively plan and support discharges from secondary care, to improve the effectiveness of multi-disciplinary team case, and also to improve patient safety when responsibility for an individual's care passes from one team or organisation to another.
- 7.13 The HSC has made good progress in these areas over the past few years but much remains to be done in order to have a truly connected and e-enabled service. The ICT implementation plan puts an onus on storing more and more service user information in digital form and providing more convenient ways of accessing this information in such a way as to improve work processes, increase the quality and timeliness of care, and facilitate flexibility in where the care is actually provided.
- 7.14 New or improved ICT is viewed as an enabling component of service change and service improvement initiatives. In view of this the Department recommends that in taking forward the implementation of the ICT strategy the needs of paediatric services are included in each project, where appropriate.

**Recommendation 21** 

In taking forward the implementation of the ICT Strategy, the Health and Social Care Board should ensure that the requirements of paediatric services are included in ICT projects where appropriate.

# Research

7.15 Ongoing research work is another necessary component to improving understanding, diagnosis, treatment, management and effective service provision. The Department therefore recommends that the proposed paediatric network should work with clinicians and academics to develop this resource.

### **Recommendation 22**

The paediatric network should work with clinicians and academics to develop research resources.

### **Robust Outcomes Data**

7.16 The availability of high quality, robust outcomes data to ensure quality outcomes for children is crucial. Performance monitoring and reporting arrangements are important tools to enable the service to evaluate and improve the integration of and access to current paediatric services. In particular it is important that information on quality of services provided to children in and outside Northern Ireland is readily available.

### 7.17 The Department therefore recommends that:

Recommendation 23

Data collection systems, including agreed definitions, should be put in place to better manage demand, capacity and outcomes of paediatric services.

# Section G: Equality and Human Rights Considerations

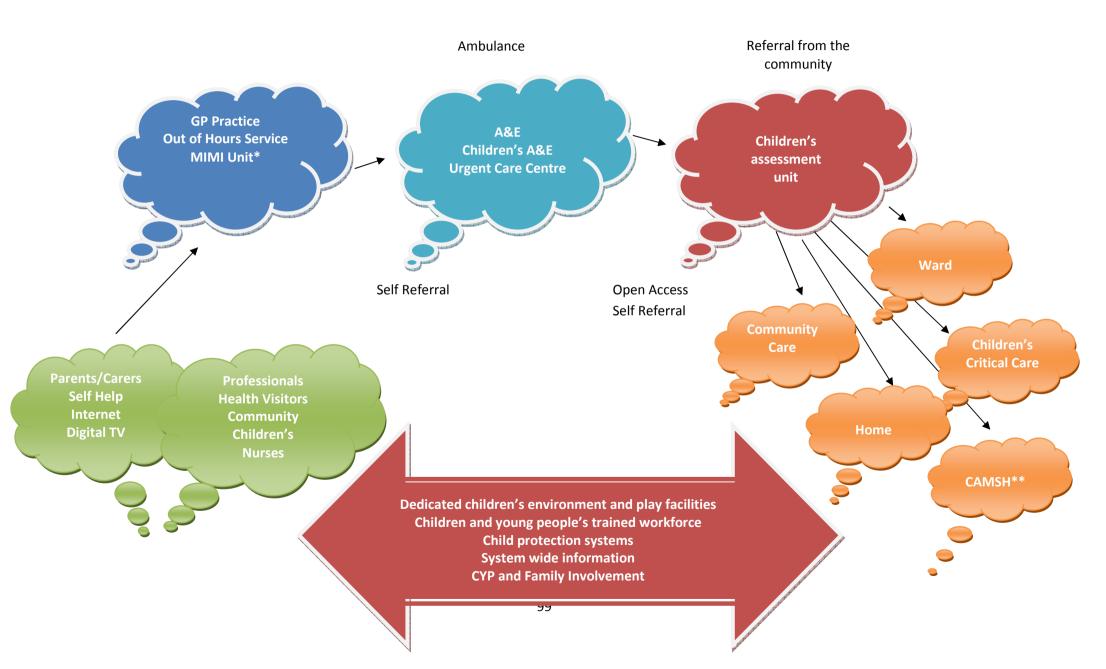
8.1 Equality and Human Rights screening has been carried out and, at this time, it is considered that the introduction of the recommendations in this Review will have no adverse impact on any of the groups mentioned in S75 of the NI Act 1991.

# **Section H: Public Consultation Arrangements**

- 9.1 The public consultation period will commence on 5 November 2013 and will run for 12 weeks closing on 31 January 2014.
- 9.2 The consultation document and consultation response questionnaire can be accessed using the following link: http://www.dhsspsni.gov.uk/index/consultations/current\_consultations.htm
- 9.3 Alternative versions of the consultation documents are available by request to the Department.
- 9.4 The closing date for submitting comments is 31 January 2014 and responses should be sent to:

Secondary Care Directorate Room 1, Annex 1, Castle Buildings Stormont Estate Belfast BT4 3SQ

E-mail: <u>secondary.care@dhsspsni.gov.uk</u> Tel: (028) 9052 0264 Fax: (028) 9052 3302



# Children and young people emergency and urgent care services illustrative diagram

\* Minor illness Minor Injury Unit \*\*Child and Adolescent Mental Health Service

# **Specialised Paediatric Services**<sup>47</sup>

This list is provided as <u>an example</u> of the range of specialised services that are required for some children and young people, some of whom are potentially the most vulnerable in our society. Many of these services have interdependencies.

- 1. Blood and bone marrow transplant;
- 2. Burns;
- 3. Cardiology;
- 4. Cardiothoraic surgery;
- 5. Clinical haematology (Non malignant);
- 6. Ear. Nose and Throat (airway);
- 7. Endocrinology;
- 8. Gastroenterology;
- 9. Immunological disorder;
- 10. Infectious Diseases;
- 11. Major Trauma;
- 12. Metabolic medicine;
- 13. Neonatology;
- 14. Nephrology;
- 15. Neurology
- 16. Neurosurgery;
- 17. Oncology( including heamato-oncology);
- 18. Paediatric critical care;
- 19. Respiratory medicine;
- 20. Specialised orthopaedic and spinal surgery
- 21. Specialised paediatric anaesthesia
- 22. Specialised paediatric surgery;
- 23. Urology;

<sup>&</sup>lt;sup>47</sup> Commissioning Safe and Sustainable Specialised Paediatric services –A framework for Critical Interdependencies (2008); Department of Health, England

# **Terms of Reference for the Review (October 2012)**

# **Review of Paediatric Services for Children and Young People**

# 1.0 Aim

The Department is undertaking a review of HSC services for all children and young people in Northern Ireland. The aim of the review is to provide a strategic direction for the future development of HSC services for children and young people (from 0-18 years) over the next ten years, recognising the interface between hospital and community services.

# 2.0 Scope of Review

The scope of this review relates to healthcare services. It will be completed in three phases and will be outcomes focussed. In recognition of the significant interface between hospital and community, the need for continuity of care and the ethos underpinning *Transforming Your Care*<sup>48</sup> including the shift of service provision from hospital to community, **Phase One** (Hospital services –supra regional, regional and area and local) and **Phase Two** (Community services) will be developed concurrently. **Phase Three** (palliative and end of life care for children with complex and life-limiting conditions) will be considered separately in order to give prominence to this important topic. However, the final document will be a single document covering the above component parts.

The Paediatric Review will recognise that individuals, parents and families are partners in care. The review will not duplicate other policies and strategies; for example, the Public Health Framework and linked public health strategies, Maternity Strategy, Healthy Futures, Long-term Conditions Framework, Physical and Sensory Disability Strategy, Bamford Action Plan, Paediatric

<sup>&</sup>lt;sup>48</sup> *Transforming Your Care* - A review of health and Social Care In Northern Ireland – December 2011

Surgery and ENT standards, and Safeguarding legislation, policies and procedures.

It will, however, recognise important interfaces especially the link between maternity, neonatal and paediatric services. A new Women's hospital is under construction and is due to be completed by December 2015 with plans for a new Children's Hospital being developed.

The desired outcomes are:

- <u>Phase 1</u> <u>Hospital Services</u> Effective, high quality, sustainable specialist, elective and emergency paediatric and neonatal care at supra regional, regional, area and local levels with enhancement of communication and transition planning, and clarity of roles and responsibilities.
- <u>Phase 2</u> <u>Community Services</u> Promotion of early intervention, enhancement of ambulatory and outreach/inreach service provision from hospital to community with effective communication pathways between primary, community and tertiary services,
- <u>Phase 3</u> <u>Palliative and end of life care</u> high quality treatment, care and support through development of multidisciplinary team approaches to meet the needs of the child and family members.

# **Objectives**

Drawing on the best available evidence, the Review Team will develop a paediatric strategy which will –

- Inform, empower and support parents, children and young people to make the best decisions and choices regarding their health and wellbeing, recognising them as partners in care;

- Define the broad scope of paediatric services and associated specialities which should be available to the population of Northern Ireland at local, area, regional and supraregional levels for children from birth to 18 years;
- Promote new ways of working and an appropriate skill mix to complement current and future population needs, recognising the importance of access to services, workforce training and development, and new technologies in the assessment, diagnosis, treatment and support of children and young people;
- Promote safe and sustainable low volume, high specialist (supraregional) paediatric services through networked and other approaches;
- Promote age- appropriate care for acute inpatient medical and surgical services for children and recognise the need for family and child friendly outpatient, day case, emergency and ambulatory care;
- Recognise the developmental, emotional and psychosocial needs of adolescents in the planning and design of services and facilities, and promote a smooth transition to adult services;
- Maximise multidisciplinary team working and partnership approaches between children's and adult services, voluntary sector, and across the primary, secondary, tertiary and supraregional service interfaces, in order to coordinate care;
- Develop a model for palliative and end of life care for children and young with complex and life limiting conditions, where care will be

delivered predominately in their own home and in the local community; and

 Make the best use of available resources and, if necessary, highlight areas where specific investment may be required in future years.

The Review will not make recommendations on the detail of the infrastructure required to deliver any proposed service model but the paediatric strategy will inform future business cases on hospital design.

# **Governance and Accountability**

The project will have an appropriate project management structure. This will link to the wider service remodelling structures being developed to take forward reform and modernisation as outlined in Transforming Your Care.

The project sponsor will be Mrs Catherine Daly, Head of Healthcare Policy Group who will report through existing governance arrangements within the Department and will also inform the Health and Social Care Strategic Planning Group which is chaired by the Permanent Secretary of the Department.

The project senior responsible owner will be Dr Maura Briscoe, Director of Strategic Projects in Healthcare Policy Group, who will lead the review project team. A list of project management board members and professional advisers is attached.

# **Timeframe for Completion**

The project will commence in autumn 2012 and, subject to Ministerial approval, will produce a phase 1 and 2 draft strategy for public consultation in early 2013.

Phase 3 will commence in late 2012/ early 2013 and a separate document will be produced for public consultation by end March 2013.

The final strategy incorporating the three phases of the Review will be brought together in a single document which, subject to Ministerial approval, will be published in early 2014.

October 2012

#### **Project Management Board/Review Group Members and Professional Advisers**

Dr Maura Briscoe - Former Director of Secondary Care, DHSSPS (Chair – until January 2013)

Ms Margaret Rose McNaughton - Former Director of Secondary Care, DHSSPS (Chair January – May 2013)

Mr Jackie Johnston - Director of Secondary Care, DHSSPS (Chair June 2013 – present)

Ms Zoe Boreland - Nursing Officer, DHSSPS

Ms Denise Boulter - Consultant Midwife, Public Health Agency

Ms Fiona Brown - Head of Children's Nursing, Northern Health and Social Care Trust

Dr Rachel Doherty - Specialist T Registrar in Public Health Medicine, Public Health Agency

Ms Lyn Donnelly - Commissioning Lead for Southern Area, Health and Social Care Board

Ms Joan Hardy - Regional Services Unit, DHSSPS

Dr Paul Jackson - Clinical Director of Children's Services, Royal Belfast Hospital for Sick Children

Dr Mike Ledwith - Clinical Director of Paediatrics, Northern Health and Social Care Trust

Dr Heather Livingston - Senior Medical Officer, DHSSPS

Dr Joanne McClean - Consultant in Public Health Medicine, Public Health Agency

Ms Sharon McCloskey - Care Services Manager, Northern Ireland Hospice

Mr Jim McComish - Regional Services Unit, DHSSPS

Tina McCrossan - Director of Children and Young People's Services, Northern Ireland Hospice

Dr George O'Neill - Chairperson of the Belfast Local Commissioning Group / GP representative

Ms Laura Smyth - Hospital Information Branch, DHSSPS

Ms Hazel Winning – AHP Officer, DHSSPS

#### **Critical Experts**

Dr Heather Payne - Senior Medical Officer, Welsh Government

Fiona Smith - Adviser in Children and Young People's Nursing, Royal College of Nursing

#### Strategic Documents

- Transforming Your Care: A Review of Health and Social Care in Northern Ireland (2011)
- A Strategy for Maternity Care in Northern Ireland 2012 2018)
- Public Health Strategy (2012-2022)
- A Fitter Future for All A Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2012-2022);
- Healthy Child, Healthy Future (2010);
- Children's Service Framework
- RQIA Review on Children on Adult Wards
- Pseudomonas Inquiry
- Review of Paediatric Congenital Cardiac Services
- Inter-hospital Transfer and Retrieval Service for Paediatric and Neonatal Transport
- Surgical Standards
- ENT standards
- A New Strategic Direction for Alcohol and Drugs
- Sexual Health Promotion Strategy (2008)
- Ten-Year Tobacco Control Strategy (February 2012);
- Family Matters; Supporting Families in Northern Ireland. Regional Family and Parenting Strategy (2009)
- Family Nurse Partnership Programme
- Physical and Sensory Disability Strategy and Action Plan (2012);
- Childcare Strategy
- Mental Health and Well-being Promotion
- Living with Long-Term Conditions a Policy Framework (2012);
- Tackling Violence at Home (2005-2013)
- Healthy Futures (2010);
- Bamford Action Plan (2009-2011)

- Review of Child and Adolescent Mental Health Services (2011)
- Promoting Good Nutrition (2011);
- Co-operating to Safeguard Children
- Bamford Action Plan 2012-15
- Child and Adolescent Mental Health Services A Service Model (DHSSPS July 2012)
- Our Children and Young People Our Pledge (OFMDFM 10 yr strategy 2006-2016)
- Children and Young People's Strategic Partnership (CYPSP) Plan 2011-2014

**Fit and Well – Changing Lives 2012-2022** - is a cross governmental draft public health strategy which was issued for consultation in July 2012. It uses a "life course" approach to analyse and understand the effects of health determinants and influences across time. It documents these determinants of health and the main interventions which can be applied to health promotion, disease prevention, diagnosis and treatment, as well as rehabilitation. In doing so it recognises the importance of whole systems approaches and intersectoral working.

*Healthy Futures 2010 - 2015 -* The Contribution of Health Visitors and School Nurses in Northern Ireland (**March 2010**)

Healthy Futures provides those working within child health services and broader stakeholders with information about the role and function of health visitors and school nurses within integrated children's services and describes the contribution of these services to improving health and reducing inequalities within the population.

## Healthy Child, Healthy Future - A Framework for the Universal Child Health Promotion Programme in Northern Ireland (May 2010)

The framework sets out a clear core programme of child health contacts that every family can expect, wherever they live in Northern Ireland, recognising that individual families are different and that there is a need to be flexible and innovative to ensure that all families are able to access and benefit from the advice, support and services that are available to them.

# Physical and Sensory Disability Strategy and Action Plan 2012 – 2015 (February 2012)

This strategy (2012 – 2015) confirms the Department's commitment to improving outcomes, services and support for people in Northern Ireland (NI) who have a physical, communication or sensory disability.

#### Living with Long Term Conditions – A Policy Framework (April 2012)

The purpose of this document is to provide a policy framework for the Health and Social Care Board (HSCB), Health and Social Care (HSC) Trusts, the Public Health Agency (PHA), the voluntary and community sectors and independent care providers that will help them plan and develop more effective services to support people with long term conditions and their carers. It provides a context within which commissioners and providers can share and extend good practice and develop and improve services and practices that deliver best outcomes for patients and carers.

#### 'Transforming Your Care' Principles

- 1. Placing the individual at the centre of any model by promoting a better outcome for the user, carer and their family.
- 2. Using outcomes and quality evidence to shape services.
- 3. Providing the right care in the right place at the right time.
- 4. Population-based planning of services.
- 5. A focus on prevention and tackling inequalities.
- 6. Integrated care working together.
- 7. Promoting independence and personalisation of care.
- 8. Safeguarding the most vulnerable.
- 9. Ensuring sustainability of service provision.
- 10. Realising value for money.
- 11. Maximising the use of technology.
- 12. Incentivising innovation at a local level.

#### Acute Services Criteria

Appendix E – acute services criteria – please revise to reflect the version consulted on in 'TYC: Vision to Action' (ie: including weightings for the criteria .

Criterion	Weight
Safety & Quality – the option:	
<ul> <li>Comfortably meets any professional standards for minimum volumes of activity</li> <li>Meets quality standards endorsed by DHSSPS or accepted by commissioners</li> <li>Supports rapid and senior clinical decision making</li> </ul>	30
<ul> <li>Meets the requirements in the Commissioner Specifications</li> </ul>	
<ul> <li>Facilitates research to further drive improvements in care</li> </ul>	
<ul> <li>Deliverability and sustainability – the option:</li> <li>Requires realistically deliverable numbers of multidisciplinary teams</li> <li>Realistically can recruit and retain the number and range of staff required, taking account of recent experience</li> <li>Is deliverable and sustainable in the context of reliance on relevant interdependent clinical services</li> <li>Supports recognised accredited training for junior medical staff</li> <li>Enables European Working Time Directive requirements to be met</li> <li>Can accommodate future new technologies</li> <li>Can be organised to deliver reliably and consistently in accordance with agreed standards</li> </ul>	25
<ul> <li>Effective use of resources – the option:</li> <li>Supports a staffing model to deliver 7 day a week working</li> <li>Maximises use of built infrastructure by minimising downtime and enables productivity improvements</li> <li>Maximises available opportunities for cross-boundary and cross-border working</li> <li>Minimises delays for inpatients and delivers against waiting time targets</li> </ul>	15
<ul> <li>Local access – the option:</li> <li>Delivers timely access to quality services according to a patient's clinical acuity/needs</li> <li>Provides services as locally as possible, where this can be done safely, sustainably and cost-effectively</li> </ul>	15
<ul> <li>Stakeholder support – the option:</li> <li>Has public and patient support</li> <li>Has clinical and other professional support</li> <li>Has the support of professional standard-setting organisations</li> <li>Has staff representative support</li> </ul>	15
	100

Admissions to HSC Hospitals in Northern Ireland under the Acute Programme of Care in 2011/12 where the patient was aged 0-17 years, by Specialty and Classification

Specialty	Specialty		Inpatient		Day Cases	Total
Code	Specially	Elective	Emergency	Other	Elective	TOLAI
100	General Surgery	105	2,488	26	583	3,202
101	Urology	54	49	4	131	238
110	Trauma And Orthopaedic	883	946	364	639	2,832
120	ENT	2,119	450	102	3,402	6,073
130	Ophthalmology	61	44	20	613	738
140	Oral Surgery	206	105	54	867	1,232
142	Paediatric Dentistry	2	0	0	323	325
150	Neurosurgery	84	69	56	33	242
160	Plastic Surgery	178	282	79	488	1,027
170	Cardiac Surgery	24	0	65	0	89
171	Paediatric Surgery	332	467	148	1,136	2,083
172	Thoracic Surgery	18	6	2	2	28
180	Accident And Emergency	0	349	0	0	349
190	Anaesthetics	13	28	50	0	91
191	Pain Management	0	0	0	6	6
300	General Medicine	20	1,073	13	177	1,283
301	Gastroenterology	2	17	0	130	149
302	Endocrinology	8	11	1	3	23
303	Haematology Clinical	2	6	2	103	113
314	Rehabilitation	2	0	4	52	58
320	Cardiology	226	107	127	108	568
330	Dermatology	34	16	0	456	506
340	Thoracic Medicine	5	5	1	1	12
350	Infectious Diseases	84	725	36	0	845
361	Nephrology	102	17	6	485	610
370	Medical Oncology	309	20	10	407	746
400	Neurology	13	18	4	42	77
410	Rheumatology	0	2	0	390	392
420	Paediatrics	793	17,824	2,449	1,347	22,413
421	Paediatric Neurology	98	59	32	14	203
502	Obs And Gyn Gynaecology	30	115	8	36	189
620	General Practice Other	18	1	0	5,426	5,445
800	Clinical Oncology	16	2	2	9	29
810	Radiology	2	0	0	115	117
823	Haematology	152	8	10	1,071	1,241
	Total	5,995	25,309	3,675	18,595	53,574

Source: Hospital Inpatient System

## Appendix G

## Variation in Age Limits on Paediatric Wards in Northern Ireland

Source: HSC Trusts 2012

Unit	General medical ward	General Surgery ward	Pre-existing condition-complex	Other reason
Antrim	<15yrs	<15yrs	Case by case basis	<16yrs for infectious disease & eating disorders
				12yrs and over in ICU ; younger children may be stabilised prior to transfer
Causeway	16 <sup>th</sup> birthday	16 <sup>th</sup> Birthday	Case by Case	12yrs and over in ICU ; younger children may be stabilised prior to transfer
Mid Ulster	n/a	n/a	n/a	n/a
Ulster	Maynard<14 yrs Craig <18 yrs ( this ward has adolescent bay) Rapid response<14yrs	Craig <13 Yrs for surgery	<18 yrs <18yrs	>14 yrs admitted to ICU
Craigavon	Up to 13 yrs and 364 days (Trust Changing for Children Strategy plans to extend this up to 15 yrs and 364 days)	Up to 13 yrs and 364 days (Trust Changing for Children Strategy plans to extend this up to 15 yrs and 364 days)	DKA up to 15 yrs 364 days, Severe chronic disease and life limiting conditions up to 17 yrs 364 days (or older in certain circumstances at discretion of the consultant)	>13 yrs admitted to ICU
Daisy Hill	Up to 13 yrs and 364 days (Trust Changing for Children Strategy plans to extend this up to 15 yrs and 364 days)	Up to 13 yrs and 364 days (Trust Changing for Children Strategy plans to extend this up to 15 yrs and 364 days)	DKA up to 15 yrs 364 days, Severe chronic disease and life limiting conditions up to 17 yrs 364 days (or older in certain circumstances at discretion of the consultant)	>13 yrs admitted to ICU CAH

Unit	General medical ward	General surgery ward	Pre-existing condition-complex	Other reason
Royal Belfast Hospital for Sick Children (RBHSC)	up to the 13 <sup>th</sup> birthday (from OP) up to 14 <sup>th</sup> birthday (from ED)	up to the 13 <sup>th</sup> birthday (from OP) up to 14 <sup>th</sup> birthday (from ED)	Variable- speciality specific:Up to 13 <sup>th</sup> birthdayBurns and plastics serviceDermatologyEndocrinologyDiabetesImmunologyInfectious DiseasesMetabolicNeurologyNeurologyOrthopaedicsUrologyUp to 14 <sup>th</sup> birthday:CardiologyCardiologyUp to end of full time education (normally 18 yrs):Cystic FibrosisHaematology - children with a first presentation after 14 years will attend BCH Renal - children with a first presentation after 14 years will attend RBHSCUp to 20: Cleft palate service	

Royal	>14 yrs generally admitted to	>14 yrs are generally admitted	Depends on the pre existing condition and the	up to 13 yrs PICU RBHSC
Victoria	the normal adult ward in a	to the normal adult ward in a	speciality. CF patients are admitted to RBHSC up	
(RVH)	side room if available	side room if available	to 18 years.	14 and 15 yrs RVH ICU
		Ward 31 usually <13 yrs but		(2011-12 6 children were admitted
		will take up to 18 yrs for ENT		totalling 31 days).
		Up to 16 yrs for		
		ophthalmology		

Unit	General medical ward	General surgery ward	Pre-existing condition-complex	Other reason
Mater (MIH)	>14 yrs generally admitted to the normal adult ward in a side room if available	>14 yrs are generally admitted to the normal adult ward in a side room if available	Depends on the pre existing condition and the speciality. CF patients are admitted to RBHSC up to 18 years.	up to 13 yrs PICU RBHSC 14 and 15 yrs ICU MIH (2011-12 1 child <16 staying 4.1 days)
Belfast City (BCH)	>14 yrs generally admitted to the normal adult ward in a side room if available	>14 yrs generally admitted to the normal adult ward in a side room if available	Depends on the pre existing condition and the speciality. CF patients are admitted to RBHSC up to 18 years.	up to 13 yrs PICU RBHSC 14 and 15 yrs ICU BCH (2011-12 1 child<16 staying 5.9 days)
Altnagelvin	up to 14 yrs (if not under the ongoing care management of paediatrician)	up to 14 yrs (if not under the ongoing care management of paediatrician)	If long term condition and not transitioned to adult services can be admitted to the children's ward, however most are transitioned by 16 years of age. Patients under gastroenterology may not be transitioned until 17. Children with very complex physical health care needs may not be transitioned if it is anticipated that they are at end of life phase, and as such some children may be admitted who are 20 years old although they remain of childlike size, weight and behaviour	<ul> <li>&lt; 13 yrs resuscitated, transferred to a theatre and prepared for transfer to a dedicated PICU</li> <li>&gt;14 yrs ICU/HDU Altnagelvin</li> </ul>
South West Acute (SWAH)	16 <sup>th</sup> birthday	16 <sup>th</sup> birthday	16 <sup>th</sup> birthday (although some leeway If still under paeds r/v, esp severely disabled children)	<13 yrs PICU 14-15 yrs ICU SWAH or ICU Altnagelvin ( if specialty input e.g. ENT not available SWAH
Tyrone County (TCH)	N/A	N/A	N/A	N/A

## **Appendix H**

#### Most Frequently Recorded Primary Diagnosis for Patients aged 0-17 Treated Electively under the Acute Programme of Care in 2011/12

Age Group (years)	Primary Diagnosis	Description	Number of Admissions	Percentage of Admissions	Average Length of Stay (days)	Total Stay Duration (days
	Z29	Need for other prophylactic measures	133	11.5%	0.0	(
	K40	Inguinal hernia	66	5.7%	0.8	34
0	Z03 Q38	Medical observation and evaluation for suspected diseases and conditions Other congenital malformations of tongue, mouth and pharynx	61 59	<u>5.3%</u> 5.1%	1.0	:
	Q65	Congenital deformities of hip	53	4.6%	1.2	5
	Z47	Other orthopaedic follow-up care	36	3.1%	0.3	2
	H65	Nonsuppurative otitis media	88	7.3%	2.5	Ę
	Z29	Need for other prophylactic measures	82	6.8%	0.0	
4	Q54	Hypospadias	47	3.9%	0.7	2
1	Q38	Other congenital malformations of tongue, mouth and pharynx	36	3.0%	2.0	4
	Z01	Other special examinations and investigations of persons without complaint or rep	35	2.9%	0.0	
	Z03	Medical observation and evaluation for suspected diseases and conditions	29	2.4%	1.0	
	K02	Dental caries	1,386	26.5%	0.8	
	H65	Nonsuppurative otitis media	479 387	<u>9.1%</u> 7.4%	0.6	
2-4	J35 J03	Chronic diseases of tonsils and adenoids Acute tonsillitis	246	4.7%	0.8	213
	C91	Lymphoid leukaemia	145	2.8%	1.4	14
	Z03	Medical observation and evaluation for suspected diseases and conditions	90	1.7%	0.5	6
	K02	Dental caries	2,785	44.7%	0.9	8
	H65	Nonsuppurative otitis media	479	7.7%	0.5	18
5-7	J35	Chronic diseases of tonsils and adenoids	402	6.5%	0.8	136
01	J03	Acute tonsillitis	275	4.4%	1.0	223
	N18	Chronic renal failure	239	3.8%	16.4	82
	C91	Lymphoid leukaemia	122	2.0%	1.5	15
	K02	Dental caries	1,203	34.2%	0.2	-
	H65 J35	Nonsuppurative otitis media Chronic diseases of tonsils and adenoids	177 173	<u>5.0%</u> 4.9%	0.7	57
8-10	J03	Acute tonsillitis	173	4.9%	0.8	112
	D66	Hereditary factor IX deficiency	146	4.1%	3.5	
	D61	Other aplastic anaemias	73	2.1%	3.0	
	K02	Dental caries	411	13.7%	0.9	-
	J35	Chronic diseases of tonsils and adenoids	149	5.0%	0.7	55
11-13	J03	Acute tonsillitis	131	4.4%	1.0	
11.10	C40	Malignant neoplasm of bone and articular cartilage of limbs	78	2.6%	4.9	
	H65 C91	Nonsuppurative otitis media Lymphoid leukaemia	70 69	<u>2.3%</u> 2.3%	0.6	35
	N18 K02	Chronic renal failure Dental caries	145 75	<u>12.7%</u> 6.6%	15.0 0.3	15
	J03	Acute tonsillitis	59	5.2%	1.1	50
14	K07	Dentofacial anomalies [including malocclusion]	50	4.4%	0.2	
	J35	Chronic diseases of tonsils and adenoids	39	3.4%	0.8	15
	C71	Malignant neoplasm of brain	33	2.9%	4.5	18
	J03	Acute tonsillitis	63	5.9%	1.0	56
	K02	Dental caries	63	5.9%	0.0	(
15	J35	Chronic diseases of tonsils and adenoids	36	3.4%	0.7	18
	K07 K01	Dentofacial anomalies [including malocclusion] Embedded and impacted teeth	35 33	<u>3.3%</u> 3.1%	0.2	
	S02	Fracture of skull and facial bones	33	3.1%	1.0	
	J03	Acute tonsillitis	63	6.2%	1.1	6
	J35	Chronic diseases of tonsils and adenoids	51	5.0%	0.7	24
10	K02	Dental caries	39	3.8%	0.0	
16	S02	Fracture of skull and facial bones	34	3.3%	2.0	
	K01	Embedded and impacted teeth	26	2.5%	0.0	
	D80	Immunodeficiency with predominantly antibody defects	25	2.4%	0.0	(
	J03	Acute tonsillitis	70	6.8%	1.0	
	J35	Chronic diseases of tonsils and adenoids	59	5.8%	1.0	
17	S02	Fracture of skull and facial bones Other disorders of nose and nasal sinuses	56	5.5%	1.5	1:
	J34 L68	Uther disorders of nose and nasal sinuses Hypertrichosis	31 26	<u>3.0%</u> 2.5%	1.1	
	K50	Crohn's disease [regional enteritis]	23	2.2%	7.0	
	K02	Dental caries	5,994	24.4%	0.6	
	H65	Nonsuppurative otitis media	1,338	5.4%	0.8	
Fotol	J35	Chronic diseases of tonsils and adenoids	1,315	5.3%	0.8	51
Total		Chronic diseases of tonsils and adenoids Acute tonsillitis Chronic renal failure	1,315 1,061	<u>5.3%</u> 4.3% 1.9%	0.8 1.0 9.2	

Source: Hospital Inpatient System

## Appendix I

## **Paediatric Emergency Departments – How Children are Managed**

Hospital	At least one staff member on duty who has attended Safeguarding Children Training	Designated Paeds area	Resus area	Urgent ST3 or above Opinion normal hours	Urgent Paeds ST3 or above Opinion – out of hours	Urgent Anaesthetic opinion Normal hours	Urgent anaesthetic opinion OOH	Minor Injuries Unit( MIU) Urgent Care and treatment Centre(UCTC)
Antrim	Yes from December 2013	Yes	Yes					
Causeway	As above.	No	Yes					
Altnagelvin	Yes	Yes but not staffed 24/7	Designated	Consultant of week Registrar bleep	SHO/reg on site Consultant, on call	Emergency anaesthetic team Initial responders (CT1-CT5) Consultant on call, but may not have paeds experience	Emergency anaesthetic team Initial responders (CT1-CT5) Consultant on call, but may not have paeds experience	Emergency Nurse practitioner cover from 9am-9pm/ 7days – Minor injuries
Tyrone County	-	-	-		-	-	-	UCTC By pass protocol in place Emergency treatment and transfer to DGHs
SWAH	Yes	Yes but not used due to lack of staff cover	Designated	Consultant of week SHO bleep	SHO on site Consultant on call	Initial responder SAS (ST3 or above) Consultant on call, but may not have paeds experience	Initial responder SAS( ST3 or above) Consultant on call, but may not have paeds experience	-

Ulster	Yes	Yes designated treatment area and waiting area	Designated APLS on every shift	Consultant of week/midd le grade of week ENT consultant	Middle grade on site Consultant on call	Paeds resus team; middle grade anaesthetist Consultant bleep		MIU -Ards/Bangor Children over 5 yrs seen within defined protocols
Craigavon	Yes	Yes	Designated Children's nurse on shift-	available 24/7 -ST3 and above; Consultant on site and 9am-1pm at w/end	ST3 and above Consultant on call	Consultant within hours on site ST3 or above	Resident ST3 or above	MIU –Armagh- sees children over 5 years old; MIU-STH – over 1 yrs old
Daisy Hill	Yes	Yes	Designated	24/7 ST3 and above on site Consultant on site and 9am-1pm	ST3 and above on site Consultant on call	Consultant within hours	Resident SAS grade on site	As above
Mater	Yes	No	No	w/ends ED Consultant Contact RBHSC	First on call and contact RBHSC	On call rota and airways advice consultant rota available in Trust	On call rota and airways advice consultant rota available in Trust	No
RVH	Yes	No	No	ED Consultant Contact RBHSC	First on call and contact RBHSC	On call rota and airways advice consultant rota available in Trust	On call rota and airways advice consultant rota available in Trust	No
RBHSC	Yes	Yes	Yes	Within ED – consultant	Within ED – consultant or	On call registrar.	On call registrar.	-

Major	or staff	staff grade	PICU informed and	PICU informed and
facilities	grade	doctor presence	consultant available;	consultant available;
including CT	doctor	9am-midnight	Airways team rota –	Airways team rota –
scanner;	presence	Mon-Fri &	comprising – ENT	comprising – ENT
	9am-	3pm-	consultant, Registrar	consultant, Registrar
All nurses	midnight	12midnight	and Anaesthetist	and Anaesthetist
are paeds	Mon-Fri &	w/ends.		
trained;	3pm-	Other times-		
2.8 WTE-	12midnight	registrar from		
ENP	w/end	hospital rota		
4WTE Band				
6; minor				
injuries				
stream 2pm-				
10pm -7 days				

## Appendix J Most Frequently Recorded Primary Diagnosis for Patients aged 0-17 years Treated Non-Electively under the Acute Programme of Care in 2011/12

Age Group (years)	Primary Diagnosis	Description	Number of Admissions	Percentage of Admissions	Average Length of Stay (days)	Total Sta Duration (days
	J21	Acute bronchiolitis	1,244	12.8%	2.7	3,35
	J06	Acute upper respiratory infections of multiple and unspecified sites	552	5.7%	1.0	
D	B34	Viral infection of unspecified site	520	5.4%	1.5	
	P59	Neonatal jaundice from other and unspecified causes	487	5.0%	2.1	,
	K21 P22	Gastro-oesophageal reflux disease Respiratory distress of newborn	412	4.2%	1.6 17.4	
						,
	B34	Viral infection of unspecified site	403	10.9%	1.1	44
	J06 A08	Acute upper respiratory infections of multiple and unspecified sites Viral and other specified intestinal infections	<u>398</u> 371	<u>10.8%</u> 10.0%	0.9	
1	J03	Acute tonsillitis	257	6.9%	1.2	
	J22	Unspecified acute lower respiratory infection	227	6.1%	2.0	
	J05	Acute obstructive laryngitis [croup] and epiglottitis	187	5.1%	0.8	15
	B34	Viral infection of unspecified site	436	8.3%	1.0	41
	J03	Acute tonsillitis	352	6.7%	1.1	
2-4	A08	Viral and other specified intestinal infections	347	6.6%	1.1	39
2-4	J06	Acute upper respiratory infections of multiple and unspecified sites	340	6.5%	1.3	
	J22	Unspecified acute lower respiratory infection	306	5.8%	2.0	
	J45	Asthma	276	5.3%	1.4	39
	S52	Fracture of forearm	150	5.8%	1.0	
	J45	Asthma	147	5.6%	1.5	
5-7	B34	Viral infection of unspecified site	140	5.4%	0.9	
	A08 J03	Viral and other specified intestinal infections Acute tonsillitis	110	<u>4.2%</u> 4.1%	0.9	10
	J03 J18	Pneumonia, organism unspecified	89	4.1%	2.9	
	R10 S52	Abdominal and pelvic pain Fracture of forearm	153	<u>8.0%</u> 6.7%	1.1	
	J45	Asthma	87	4.5%	1.1	
8-10	K35	Acute appendicitis	80	4.2%	2.6	
	B34	Viral infection of unspecified site	66	3.4%	0.8	
	K59	Fissure and fistula of anal and rectal regions	60	3.1%	1.5	
	R10	Abdominal and pelvic pain	221	11.1%	1.4	30
	S52	Fracture of forearm	137	6.9%	1.4	
11-13	K35	Acute appendicitis	113	5.7%	2.7	30
11-15	E10	Insulin-dependent diabetes mellitus	86	4.3%	2.2	
	K59	Fissure and fistula of anal and rectal regions	58	2.9%	2.0	
	J45	Asthma	57	2.9%	2.0	11
	R10	Abdominal and pelvic pain	113	12.7%	1.7	
	K35	Acute appendicitis	56	6.3%	2.9	
14	T39 S82	Poisoning by nonopioid analgesics, antipyretics and antirheumatics	30	<u>3.4%</u> 2.9%	1.0	
	J03	Fracture of lower leg, including ankle Acute tonsillitis	20	2.9%	0.9	
	S52	Fracture of forearm	25	2.8%	1.2	
	R10	Abdominal and pelvic pain	112	12.9%	1.8	
	K35	Acute appendicitis	42	4.8%	2.8	
	T39	Poisoning by nonopioid analgesics, antipyretics and antirheumatics	38	4.4%	0.8	
15	F10	Mental and behavioural disorders due to use of alcohol	22	2.5%	1.1	
	S09	Other and unspecified injuries of head	21	2.4%	0.6	
	E10	Insulin-dependent diabetes mellitus	20	2.3%	1.8	3
	R10	Abdominal and pelvic pain	97	9.9%	2.1	20
	T39	Poisoning by nonopioid analgesics, antipyretics and antirheumatics	62	6.3%	0.8	
16	K35	Acute appendicitis	48	4.9%	2.8	
	J03	Acute tonsilitis	26	2.7%	1.8	
	R55 S09	Syncope and collapse Other and unspecified injuries of head	20	2.0%	0.9	
	R10	Abdominal and pelvic pain	88	8.0%	2.1	
	K35 T39	Acute appendicitis Poisoning by nonopioid analgesics, antipyretics and antirheumatics	<u>64</u> 59	<u>5.8%</u> 5.4%	2.9	
17	J03	Acute tonsillitis	31	2.8%	1.1	
	E10	Insulin-dependent diabetes mellitus	26	2.4%	1.2	
	T43	Poisoning by psychotropic drugs, not elsewhere classified	24	2.2%	1.1	
	B34	Viral infection of unspecified site	1,658	5.7%	1.2	
	J06	Acute upper respiratory infections of multiple and unspecified sites	1,436	5.0%	1.2	
T-+-1	J21	Acute bronchiolitis	1,296	4.5%	2.7	,
Total	A08	Viral and other specified intestinal infections	1,289	4.4%	1.2	
	J03	Acute tonsillitis	1,015	3.5%	1.1	1,13
	R10	Abdominal and pelvic pain	936	3.2%	1.5	1,4

Source: Hospital Inpatient System

### Appendix K

## <u>Allied Health Professional staffing – South Eastern Health and Social Care</u> <u>Trust</u>

Allied Health Professional staffing – South Eastern Health and Social Care Trust Community setting

South Eastern Health and	Ba	nd 5	Ba	nd 6	Ba	and 7	Ba	nd 8	Bar	nd 9
Social Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	-	3.0	-	3.0	-	1.5	-	-	-	-
Occupational therapy	4	6.0	5	6.70	7	4.96	1	1	-	-
Nutrition and Diet Therapy	-	-	1	0.1	2	0.6	-	-	-	-
Speech & Language	7	7.80	11	6.60	21	17.12	15	11.78	-	-
Therapy										

#### Allied Health Professional staffing – South Eastern Health and Social Care Trust Inpatient/outpatient setting

South Eastern Health and	Ba	Band 5		Band 6		Band 7		nd 8	Band 9	
Social Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	-	-	-	0.5	-	-	-	-	-	-
Occupational therapy	-	-	-	-	-	-	-	-	-	-
Nutrition and Diet Therapy	-	-	1	0.5	2	1.17	-	-	-	-
Speech & Language Therapy	-	-	-	-	-	-	-	0.1	-	-

#### Allied Health Professional staffing – Western Health and Social Care Trust

#### AHP staffing – Western Health and Social Care Trust Community setting

Western Health and Social	Ba	nd 5	Ba	nd 6	Ba	and 7	Ba	nd 8	Bar	nd 9
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	1	1.0	7	5.79	1	1.0	1	0.3	-	-
Occupational therapy	3	3.0	4	2.5	-	-	1	1	-	-
Nutrition and Diet Therapy	-	-	4**	3.1	-	-	-	-	-	-
Speech & Language	8	6.12	9	7.52	9	8.33	11	7.80	-	-
Therapy										

Allied Health Professional staffing – Western Health and Social Care Trust Inpatient/Outpatient setting

Western Health and Social	Ba	Band 5		Band 6		Band 7		nd 8	Band 9	
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	-	-	-	-	1	0.1	1	0.1	-	-
Occupational therapy	-	-	-	-	-	-	-	-	-	-
Nutrition and Diet Therapy	-	-	4**	3.1	-	-	-	-	-	-
Speech & Language	-	-	-	-	-	-	1	0.4	-	-
Therapy										

\*\*<u>Note</u>: With regard to Nutrition and diet therapy there is 4 staff who cover both inpatient/outpatient and community

#### Allied Health Professional staffing – Southern Health and Social Care Trust

## Allied Health Professional staffing – Southern Health and Social Care Trust Community setting

Southern Health and Social	Ba	Band 5		Band 6		Band 7		Band 8		id 9
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	-	-	2	1.8	16	11.36	1	1.0	-	-
Occupational therapy	3	2.75	-	-	13	9.36	2	2.0	-	-
Nutrition and Diet Therapy	-	-	-	-	-	-	-	-	-	-
Speech & Language	10	9.7	14	11.9	5	4.13	16	12.34	-	-
Therapy										

Southern Health and Social	Ba	Band 5		Band 6		Band 7		nd 8	Band 9	
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	•	-	-	-	-	-	-	-	-	-
Occupational therapy	-	-	-	-	-	-	-	-	-	-
Nutrition and Diet Therapy	-	-	4	2.21	1	0.6	-	-	-	-
Speech & Language	-	-	-	-	-	-	-	-	-	-
Therapy										

AHP staffing – Southern Health and Social Care Trust, inpatient/outpatient

#### Allied Health Professional staffing – Northern Health and Social Care Trust

AHP staffing – Northern Health and Social Care Trust Community setting

Northern Health and Social	Ba	Band 5		Band 6		Band 7		Band 8		nd 9
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	2	1.5	6	4.3	16	10.56	-	-	-	-
Occupational therapy	12	9.7	15	10.6	2	1.5	-	-	-	-
Nutrition and Diet Therapy	-	-	-	-	3	2.5	-	-	-	-
Speech & Language	-	-	1	1.0	3	1.48	-	-	-	-
Therapy										

#### Allied Health Professional staffing – Northern Health and Social Care Trust Inpatient/Outpatient setting

Northern Health and Social	Band 5		Ba	Band 6		Band 7		nd 8	Band 9	
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	•	-	-	-	-	-	1	0.5	-	-
Occupational therapy	-	-	-	-	-	-	-	-	-	-
Nutrition and Diet Therapy	-	-	-	-	-	-	-	-	-	-
Speech & Language	-	-	-	-	-	-	-	-	-	-
Therapy										

## <u>Allied Health Professional staffing – Belfast Health and Social Care</u> <u>Trust</u>

Allied Health Professional staffing – Belfast Health and Social Care Trust Community setting

Belfast Health and Social	Ba	Band 5		Band 6		Band 7		Band 8		id 9
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	2	2	27	19.79	3	2.0	-	-	-	-
Occupational therapy	-	-	2	2.0	5	4.0	-	-	-	-
Nutrition and Diet Therapy	-	-	2	0.45	1	0.15	-	-	-	-
Speech & Language	-	-	4	3.6	5	4.1	3	2.63	-	-
Therapy										

#### Allied Health Professional staffing – Belfast Health and Social Care Trust Inpatient/Outpatient setting

Belfast Health and Social	Ba	Band 5		Band 6		Band 7		nd 8	Band 9	
Care Trust AHP	HC	WTE	HC	#WTE	HC	WTE	HC	WTE	HC	WTE
Physiotherapist	2	2.0	3	2.7	11	7.1	-	-	-	-
Occupational therapy	1	1.0	2	0.8	2	1.3	2	0.9	-	-
Nutrition and Diet Therapy	-	-	4	3.5	8	4.85	1	0.94	-	-
Speech & Language	-	-	-	-	1	0.5	4	2.5	-	-
Therapy										

#### **General Paediatric Surgery (GPS)**<sup>49</sup>

GPS is surgical treatment of relatively common disorders that usually do not require the resources of a specialist surgical unit. These include the following:-

Elective procedures:

- Herniotomy for congenital inguinal hernia and hydrocele;
- Orchidopexy for the palpable undescended testis;
- Circumcision;
- Removal of minor soft tissue abnormalities; and
- Repair of umbilical hernia.

Emergency procedures:

- Appendectomy;
- Correction of torsion of testis or adnexae;
- Operation for incarcerated inguinal hernia;
- Pyloromyotomy;
- Less common trauma.

It must be noted that when consideration is given as to which procedure are specialist, children and young people with significant co-morbidities may need specialised paediatric care, even for straight forward procedures.

<sup>&</sup>lt;sup>49</sup> Adapted from the **All Wales Anaesthesia and Surgery Standards,** for Children and Young People's Specialised Healthcare Services