



Department of Health

PROVIDING HIGH QUALITY HEALTHCARE FOR CHILDREN AND YOUNG PEOPLE

A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 – 2026)

Alternative Formats

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CONTENTS

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Section		<u>Page</u>
Key Facts		6
1.	Introduction	8
2.	Overview	9
3.	Strategic Context	15
4.	Our Journey So Far	17
5.	Current Service Provision	19
6.	Vision	28
7.	Mission	28
8.	Strategic Principles, Improvement Themes, Objectives	29
9.	Strategic Objectives	32
10.	Working Together to Implement the Strategy	55
11.	Equality Screening	55
Annex 1: Summary of Strategic Objectives		
Annex	2: Project Management Board	

Ministerial Foreword

As set out in the Executive's Programme for Government, a key mark of any society is the priority it attaches to giving its youngest citizens the best start in life. This is about doing everything we can to make sure that all of our children and young people grow up safely, healthily and happily in a society where they receive the support they need to achieve their full potential.

Children and young people are major users of health services, both in primary care and in hospitals. This Strategy therefore recognises the importance of the commissioning and delivery of health services for children and young people from birth up to the age of 18 years by setting out the strategic direction for the development of these services over the next ten years. The Strategy builds upon our existing high quality paediatric health services delivered across the North by clinicians and professional staff who are dedicated to improving the health of their patients.

The Strategy recognises that health services for children and young people have undergone considerable change in the last decade and that further changes are anticipated in the years ahead. These include: changing population health needs; the increasing complexity of conditions; the need to maintain recognised standards of good practice; and, the opportunity presented by greater innovation in the delivery of healthcare. Health and Social Care should therefore continue to provide the appropriate services, support, setting and location to best meet the needs of children, their families and carers. However, as technology develops, this should support increased levels of care in the community including "near patient testing", telemonitoring and teleconferencing linked to specialist hospital advice and support. The Strategy therefore emphasises the need to strengthen the links between community and hospital services, and services within and between hospitals. This means that most children who become ill or suffer a minor injury can be cared for by a further developed primary and community service alongside hospital services able to rapidly assess, diagnose and manage children who present with more serious illnesses and injuries.

The implementation of the Strategy will be taken forward fully aligned with the priorities and objectives for the transformation of the Health and Social Care system as set out in 'Health And

Wellbeing 2026: Delivering Together' with the clear aim of delivering better health and wellbeing outcomes for children in the north of Ireland.

Michelle O'Neill, MLA Minister of Health

Key Facts

Asthma & Allergy

• Asthma and allergies are the most commonly diagnosed long-term conditions in children. Around 1 in 7 children (14%) in the North have been diagnosed with asthma.

Attendances at Emergency Departments

 There are around 145,000 Emergency Department (ED) attendances each year by children under 16. This is 20% of total attendances at EDs. The main reasons for attendance at EDs, usually by self-referral or GP referral, relate to acute infection or injury.

Childhood Obesity

Based on 2012/13 data obtained from the Child Health System, more than a fifth (22%) of children in Primary 1 were overweight (17%) or obese (5%). In Year 8 the proportion of overweight and obese children was higher at 28%, with 21% overweight and 7% obese.

Diabetes

Around 1,000 children here 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.

Emergency Admissions to Hospital

 The most frequently recorded diagnosis for emergency admissions of under-18s in 2013/14 was viral infection of unspecified site with 1,808 admissions (7.3%). Within the ten most common diagnoses, other disorders of the urinary system had the longest average length of stay at 3.2 days.

Epilepsy

Around 2,000 children in the North have epilepsy.

Health Inequalities and Deprivation

- Children from areas with higher deprivation have poorer health than those from more affluent areas including higher unplanned hospital admission rates.
- Low breastfeeding rates, high levels of maternal smoking, and low birth weight are all more common in areas with the highest relative deprivation.

Long-term Conditions

 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.

Smoking

 In 2013 a survey revealed that by the age of 16, 29% of young people were either smoking or had smoked. 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, and higher mortality.

Rare Diseases

 There are less than 0.4m children here aged 0 to 15 years which creates significant challenges in providing specialist care for relatively very small numbers of children with rare or specialist conditions.

1. Introduction

- 1.1 This Strategy document has been prepared by the Department of Health (referred to in the document as "DoH" or "the Department")¹ following a review of healthcare services for children and young people and a public consultation in 2013. The review team was led by the Department and comprised of healthcare professionals. The document sets out the strategic direction for paediatric community and acute care for the next ten years.
- 1.2 For the purposes of this Strategy, 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.
- 1.3 By "paediatric services" we mean health services delivered to babies, children and young people from birth to their 18th 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 Strategy 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. The healthcare needs of children and young people with complex conditions are also included in the Strategy.
- 1.4 A separate strategic document covering palliative and end-of-life care for children with complex and life-limiting conditions will also due be published in 2016.

¹ Publications attributed to "DHSSPS" in this document refer to the Department of Health, Social Services and Public Safety, the former name for the Department of Health, prior to May 2016.

2. Overview

- 2.1 In 2013/14, there were approximately 52,000 admissions of under-18s to Health and Social Care sector hospitals, representing 9.7% of all admissions under the acute programme of care. The largest category of admission was within the Paediatrics specialty, comprising 43.2% (22,448) of all acute admissions of under-18s. Within this category, the vast majority of admissions were as inpatients and 20,300 (90.4%) were non-elective admissions. ENT was the next highest category of admission of under-18s (5,776); 60.6% of these were as day-cases.
- 2.2 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.
- 2.3 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 Strategy and the *Strategy for Maternity Care 2012-2018*², and other public health strategies. We recognise 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 on the Rights of the Child.
- 2.4 The Strategy therefore recognises that the needs of children, young people, their families and carers should be at the forefront of 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.

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² A Strategy for Maternity Care 2012-2018, DHSSPS, 2012.

2.5 The Strategy recognises that:

- 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
 children's nurses, midwives, health visitors, social workers, allied health
 professionals, community pharmacists and general dental practitioners;
- around 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.
- 2.6 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.
- 2.7 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 children's nurses, allied health professionals, social workers 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.
- 2.8 This Strategy 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.

2.9 HSC Services for children and young people broadly cover:

<u>Healthy Child, Healthy Future³ 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.

<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, such as 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 into adult health services.

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³ Healthy Child, Healthy Future - A Framework for the Universal Child Health Promotion Programme, DHSSPS, 2010.

Drivers for Change in Paediatric Services

- 2.10 The Department believes that change is inevitable in paediatric services, 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.
- 2.11 There is, therefore, a real need to embrace change and manage it in a co-ordinated way which is the purpose of this Strategy. The Department believes that the strategic objectives (see Section 9) in this Strategy will further improve the delivery of a quality, safe and sustainable service for children, young people and parents of the future.
- 2.12 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 technology⁴. 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 wellbeing unless identified early and managed appropriately, for example, obesity, diabetes, asthma, and allergies;

⁴ This would also include foetal medicine which specialises in the health of the foetus. It offers screening, diagnosis, and treatment of complications which may arise pre-birth.

12

- 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;
- 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 shortage of paediatric specialists in Britain and the north of Ireland, especially
 in some smaller paediatric sub-specialities leading to services not being
 sustainable in all areas and where single-handed practice will not deliver highquality, sustainable care on a 24/7 basis;
- The need to enhance and recognise the importance of 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 are
 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, dentists and other primary care
 professionals; and,

- Research, enquiries⁵ and evidence of good practice continues to change how services are delivered, with organisations such as the National Institute for Health and Care Excellence (NICE), General Medical Council (GMC), Nursing and Midwifery Council (NMC) and the Royal Colleges producing standards and guidance to promote safer and more effective treatment and care.
- 2.13 All of these drivers for change will impact on how paediatric services will be delivered in the future. There are also a number of Departmental policies, strategies and frameworks, which impact on the general health and wellbeing of children and young people and on HSC provision.

New Children's Hospital

- 2.14 Within the period covered by this Strategy we anticipate that a new Children's Hospital for the region will be completed in 2020/21. The new Children's Hospital will provide services to children up to the age of 18 years. The hospital is to be built on a site adjacent to the new Belfast Trust Maternity Hospital, parallel with the Falls Road. The Children's Hospital will contain:
 - 155 inpatient beds
 - 48 beds for day-case, short-stay assessment unit, clinical decision making unit and programmed treatment unit
 - 10 theatres (6 inpatient and 4 day case)
 - ED to accommodate 45,000 attendances per year
 - Imaging and support accommodation, and
 - Outpatient department to accommodate 53,000 attendances per year.
- 2.15 The total cost of the project, including enabling works, construction and site infrastructure works, is approximately £250million.

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⁵ 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, http://www.HQIP.org.uk

3. Strategic Context

- 3.1 The priorities within the Executive's draft *Programme for Government 2016-2021*⁶ framework which have a direct and/or indirect impact on the lives of children and young people provide the context for this Strategy. Of particular note are the outcomes:
 - We give our children and young people the best start in life; and
 - We enjoy long, healthy, active lives.
- 3.2 The Executive's priorities for children and young people are underpinned by the United Nations Convention on the Rights of the Child (UNCRC)⁷. Whilst the standards of the UN Convention are not legally enforceable, in 1991 the British Government committed itself to working towards the realisation of the rights of children.

Linkage to other DoH Strategic Documents

- 3.3 While the focus of this Strategy 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 published by the Department, the aims of which contribute to fulfilling some of the goals outlined in paragraph 3.1 above. These are:
 - Health and Wellbeing 2026 delivering together (2016)
 - Transforming Your Care (2011)⁸
 - Quality 2020 (2011)⁹
 - E-Health (which is ongoing)
 - Draft Service Framework for Children and Young People (which is under development)
 - DHSSPS General Paediatric Surgery Standards (2010)
 - DHSSPS Paediatric ENT Standards (2010)

⁶ https://www.northernireland.gov.uk/sites/default/files/consultations/newnigov/draft-pfg-framework-2016-21.pdf.

⁷ UN Convention on the Rights of the Child, 1989.

⁸ Transforming Your Care: A review of Health and Social Care, Health & Social Care Board, 2011.

⁹ Quality 2020 - A 10-year Strategy to Protect and Improve Quality in Health and Social Care, DHSSPS, 2011.

- 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)
- HSCB Review of Paediatric Congenital Cardiac Services (2013)
- International Working Group Assessment of a potential all-island model for congenital cardiac services to meet the respective needs of the populations of Northern Ireland and the Republic of Ireland (2014).

4. Our Journey So Far

- 4.1 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.
- 4.2 Most children and young people in the North can expect to live longer, healthier lives than ever before. In the 2011/12 Health Survey¹⁰, 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.
- 4.3 The number of persons aged 0-17 in the region has decreased by 4.6%, from 451,514 in the 2001 Census to 430,7632 in the 2011 Census. 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. 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. 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.
- 4.4 The last comprehensive review of health service provision for acutely ill children and young people took place in 1999¹¹. 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 18th birthday) to ensure that treatment and care is of a high standard and is available to individuals and families when they need it.

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¹⁰ The Health Survey, NISRA.

¹¹ Hospital Services for the Acutely III Child, Nursing Services for the Acutely III Child in , and Paediatric Surgical Services , DHSSPS, 1999.

- 4.5 In 2012, the Department published a *Strategy for Maternity Care 2012-2018*¹². 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 the North.
- 4.6 The Department now wants to move forward to the next stage of health service provision for children and young people. The aim of this Strategy is therefore 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 parents to make informed decisions and choices regarding their treatment and care.
- 4.7 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.
- 4.8 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 one quarter of all children will be admitted to hospital during their first year of life. There are also a significant number of children who have long-term conditions, such as 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.

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¹² A Strategy for Maternity Care 2012-2018, DHSSPS, 2012.

5. 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 children¹³), community pharmacists, dentists, optometrists and community teams, such as 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:
 - emergency/urgent care 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;
 - <u>paediatric surgery</u> both unscheduled and planned. For example, inpatient, daycase, 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, such as 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.

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¹³ Royal College of General Practitioners

Age Limits for Paediatric Medical and Surgical Services

5.4 Within the HSC system, there is variability of age limits for paediatric admissions to hospitals. 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 years from their emergency department (ED). Most district general hospital (DGH) paediatric units admit up to the 16th birthday. Such variability makes access and the co-ordination 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 18th birthday.

Inpatients and Day-Cases

- 5.5 Many factors influence demand demography, population distribution, birth rates, deprivation, and the epidemiology of disease.
- In recent years, the pattern of service provision has changed, with a decrease in the number of emergency and planned hospital admissions. In 2013/14, there were approximately 52,000 admissions of under-18s to HSC hospitals, representing 9.7% of all admissions under the acute programme of care. The largest category of admission was for Paediatrics, comprising 43.2% (22,448) of all acute admissions of under-18s. Within this category, the vast majority of admissions were as inpatients and 20,300 (90.4%) were non-elective admissions. ENT was the next highest category of admission of under 18s (5,776); 60.6% of these were as day cases.
- 5.7 Inpatient paediatric services are provided at DGHs: Antrim Area, Altnagelvin, Causeway, Craigavon Area, Daisy Hill, South West Acute, and the Ulster Hospitals. The Royal Belfast Hospital for Sick Children (RBHSC) is the region'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.

5.8 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 within certain specialist centres in Britain.

HSC Capacity in Paediatrics

- 5.9 Ambulatory beds are usually used for the acute management of patients as part of a rapid response to need, such as 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.
- 5.10 The occupancy level of available beds is also important¹⁴. Occupancy of available beds within specialty 420 (Paediatrics) ranged between approximately one third and three quarters during 2013/14. Causeway, Altnagelvin Area and South West Acute Hospitals had occupancy below 50% (33.5%, 43.6% and 49.9%, respectively). The highest occupancy rate was observed in Ulster Hospital at 73.0%. Today's occupancy rates are broadly similar to those at the time when this strategic review was carried out in 2012/13.

Paediatric Intensive Care Unit (PICU)

There is one paediatric intensive care unit in the North 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.

¹⁴ 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.

Neonatal Care

- 5.12 Each year about 2,000 babies born here will need extra care and will be admitted to a neonatal unit¹⁵. 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.
- 5.13 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, such as receiving help with their breathing or intravenous feeding; and
 - <u>Level 3</u> Special care for babies who could not reasonably be looked after at home by their mother, perhaps 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 maternity ward setting.
- 5.14 A number of recommendations from the *Independent Review of Incidents of Pseudomonas Aeruginosa in Neonatal Units* (2012) are being implemented at HSC Trust and regional levels to improve care, transport and reduce the risk of infection.

Outpatient Clinics

5.15 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

¹⁵ Neonatal Intensive Care Outcomes Research and Evaluation (NICORE).

number of clinics delivered as an outreach from RBHSC and other hospitals to local communities. 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. 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. 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

- 5.16 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.
- 5.17 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 the region and better outcomes can be achieved through networked approaches either with specialist centres within Britain or Ireland. This includes epilepsy surgery, hepatology (liver), complex neurology, and some nephrology services. A network manager has been appointed in RBHSC to oversee the co-ordination of specialist services for those children whose services cannot be delivered locally.

Community Services

5.18 There are a range of paediatric services delivered in the community. These services adopt a multi-disciplinary approach including community paediatricians, community

children's 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. Community paediatric services provide care for children with a range of conditions. Social work is an important element of multidisciplinary community based services, whether through children's disability teams, family support or hospital social work teams. There are specific clinics for childhood asthma, diabetes, attention deficit hyperactivity disorder, epilepsy, neurodevelopmental conditions, autism spectrum disorder, feeding problems, eneurisis (bed wetting), constipation, audiology, eye care and speech, language and communication services. Also, the overlap with palliative and end-of-life care services is very important.

Child and Adolescent Mental Health Services

5.19 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 CAMHS and hospitals provide an essential mechanism for the care and treatment of these patients within an acute hospital setting.

Children with Special Needs

5.20 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.

Children at Risk

5.21 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 largest category of risk to children is however that of neglect and issues such as non-organic failure to thrive or weight-faltering. Further action will be taken to develop the interface between paediatric services and the Sexual Assault and Referral Centre as required.

Children Living with Complex Physical Needs

- 5.22 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. There are 500 children living with complex needs, as defined by NI Paediatric Nursing Tool which is used throughout the region to assess needs not just of the child, but also for the social and emotional assessment of the individual, parents and carers¹⁶.
- 5.23 For the purposes of this Strategy 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.
- 5.24 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 ongoing 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

- 5.25 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, can work in both hospital and community settings, or be located in the community as part of a team-based approach to care.
- 5.26 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

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www.dhsspsni.gov.uk/developing_services_to_children_july_2009.pdf

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.

Medical Staffing

5.27 All HSC consultants and non-consultant doctors are employed by HSC Trusts. Consultant paediatricians are specialists in caring for children. In addition, there is a range of doctors in training who, as part of their postgraduate training, provide HSC services within 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. Across Britain and the North there is an increasing tendency for sub-specialisation. This, together with new working patterns, makes sustaining services and rotas difficult, particularly in smaller units.

Nursing

- 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, such as management of fluids in children up to 16 years, management of Diabetic Ketoacidosis (DKA) and safeguarding. Although there is a high skill mix in the community, this needs more development in acute services. The role of advanced children's nurse practitioners is working well across Britain, but is less developed locally. In most local 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 fully developed.
- 5.29 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 appropriate training of neonatal nurses to meet future service requirements is essential.

Allied Health Professionals (AHPs)

5.30 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 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.

Social Workers

5.31 Social work, and specifically hospital social work, has a significant role to play, particularly in assisting in the facilitation of discharge from hospital and supporting families in the community.

Voluntary Sector

5.32 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.

6. Vision

6.1 The Department's vision is:

To deliver paediatric services in accordance with the evidence of best practice and a philosophy of "locally where possible - specialist where necessary", based on a 'whole systems' approach to ensure that children living across the North have equity of access to high-quality paediatric services.

7. Mission

7.1 The Department's mission is:

To ensure that children and young people living in the North will thrive and look forward with confidence to the future, and that every child will be treated in the most appropriate setting, with access to appropriate care according to their needs.

8. Strategic Principles, Improvement Themes, and Objectives

8.1 There are seven principles designed to shape the future direction of paediatric care; these underpin 23 strategic objectives grouped under 12 improvement themes to drive improvement in care, quality and service delivery. The 23 strategic objectives aim to enable, deliver and sustain further improvement in paediatric community-based and acute services.

Strategic Principles

8.2 The implementation of the Strategy is to be guided and underpinned by seven principles designed to shape the future direction of paediatric community-based and acute care.

These are:

Clinical leadership - children should have their care clearly co-ordinated by a team, normally the paediatric team, but on occasions care will need to be led by the most appropriate clinical speciality that should have access to paediatric advice;

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;

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.

Improvement Themes

- 8.3 The 12 improvement themes designed to drive improvement in care and service delivery are:
 - 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
 - Workforce development and training
 - Imaging and Diagnostics
 - Information Communication and Technology (ICT)
 - Research
 - Robust Outcomes Data.

Strategic Objectives

8.4 The 23 strategic objectives, which aim to enable, deliver and sustain further improvement in paediatric community-based and acute services, are summarised in Annex 1 and set out in detail in Section 9 below. They include key enablers to help support the changes envisaged in this Strategy.

9. Strategic Objectives

Theme 1

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

Objective 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.

- 9.1 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. Children with good continuity of care are less likely to attend emergency departments and be admitted to hospital.
- 9.2 At all times the children, their parents and families should therefore be given information to allow them to be involved in making decisions about their treatment and care. In addition, alternative models of urgent care will provide for enhanced access to services when needed, especially in areas of high deprivation.

Objective 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.

9.3 Primary care professionals such as GPs, pharmacists, dentists, 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. 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. Early interventions, self-management, treatment, care and support are 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. The Integrated Care Partnerships (ICPs) should also contribute to an HSC holistic approach in providing services for children with long-term conditions.

Objective 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.

9.4 Health and Social Care should provide the appropriate services, support, setting and location to best meet the needs of children, their families and carers. As technology continues to improve, this should support care in the community making use of these technologies, to manage children in the community linked to specialist hospital advice and support.

Theme 2

Networked Approaches to the Delivery of Paediatric Services

Objective 4

A regional Paediatric Managed Clinical Network should be established to ensure equity of access to high-quality services across the North. The Network would include commissioners, providers, clinicians, social workers and patient representatives and should work closely with the voluntary and community sector. The Network should:

- (a) include a surgical sub-group to support the safe delivery of paediatric surgical services across the North in line with the Department's standards for general paediatric surgery;
- (b) include a paediatric imaging sub-group to support the safe delivery of paediatric imaging services across the region in line with the emerging DoH standards for imaging;
- (c) include a paediatric palliative care subgroup to take forward the implementation of the Paediatric Palliative and End of Life Care Strategy;
- (d) 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;
- (e) consider a formal relationship between the paediatric network, the neonatal network and Integrated Care Partnerships in order to establish firm linkages; and
- (f) work with clinicians and academics to develop research resources.
- 9.5 The HSC, along with other health and social care systems nationally and internationally, 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 Department believes that the development of a regional paediatric network offers the best opportunity to deliver paediatric services

in accordance with the evidence of best practice. It will also help to ensure that children living across the North 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 offers 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.

- 9.6 The Department believes that to deliver this vision, the managed clinical network should be constituted as an operational network, similar in role and function to the Critical Care Network. This would help to ensure that paediatric resources are used to maximum effect. The development of an operational network would also help to ensure that children from across the region have equitable access to the tertiary paediatric services based in Belfast.
- 9.7 Effective commissioning is a key requirement in promoting any change in service provision. A regional paediatric network involving a range of commissioners, practitioners, and user representatives 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.
- 9.8 The initial terms of reference for the regional Managed Clinical Paediatric Network are:
 - to 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;

- to 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;
- to further build into core paediatric service provision a shift towards prevention, early identification and early intervention of paediatric conditions. 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;
- o to build on the relationships that have been developed with the voluntary and community sectors in order to add value to the care of children.

Theme 3

Age-Appropriate Care

Objective 5

Children (from birth up to 16th 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. In all cases, children and young people should have treatment and care delivered to them in an age-appropriate environment to meet their physical, emotional, social, spiritual, educational and psychological needs.

To address the clinical and safeguarding issues for children in an adult inpatient setting, HSC Trusts should put in place a system that records these children and ensures paediatric input to their care.

- 9.9 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, 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. 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. The Department also recognises that there may be occasions when there is a clinical reason for a child to be cared for in an adult service.
- 9.10 The RQIA's Baseline Assessment of the Care of Children Under 18 Admitted to Adult

 Wards (2012) report highlighted that, in 2009-2010, 3,933 children aged under 18 were

 being cared for on adult wards (these were mostly adolescents).
- 9.11 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.
- 9.12 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.
- 9.13 For young people aged 16 and 17 clinical need, flexibility and choice will therefore 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.

Theme 4

Improving access to urgent and emergency treatment and care

Objective 7

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.

- 9.14 Managing acute demand is a key element of all urgent and emergency care pathways. Models in use in Britain 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) 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.
- 9.15 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.

Objective 8

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)¹⁷
- · 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.
- 9.16 A child or young person attending a hospital ED needs to be seen quickly in an ageappropriate setting and by skilled professionals. The skill and competence of staff are of the upmost importance.
- 9.17 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 the HSC 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

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 $^{^{17}}$ Maximising Nursing Skills in caring for children in Emergency Departments, RCN, 2010.

appropriate management and communication protocols including onward referral to appropriate services.

Objective 9

Emergency Departments that accept children aged 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.

9.18 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 ED 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 EDs or paediatric units. HSC Trusts need to manage such risk appropriately, and regularly communicate with the public, the Ambulance Service, GPs and other primary and community practitioners about what services are available in each ED.

Objective 10

Emergency Departments that accept children aged 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.

9.19 A physical environment which separates children and young people from adults should be incorporated into commissioning and redesign of 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.

Theme 5

Improving the Access and Quality of General Paediatric Services

Objective 11

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)¹⁸ within four hours of admission and by a consultant within 24 hours of admission. This will be kept under review by the Managed Clinical Network (see Objective 4).

*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.

- 9.20 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 inpatient admission.

 However, 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.
- 9.21 As paediatric medicine changes, the boundaries between traditional hospital and community-based care have become less well defined. Therefore, the proposed regional paediatric network will 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-

¹⁸ Advanced nurse practitioner, staff grade or associate specialist doctor or Doctor in training at ST4 or higher.

professional paediatric network, there will be a paediatric medicine sub-group to coordinate elective and emergency paediatric medicine.

Objective 12

There should be continued progress towards implementation of the *General Paediatric Surgery and ENT standards* (DHSSPS, 2010). 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 surgeon for general paediatric surgery, in the local district general hospital, 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.

Objective 13

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 Royal Belfast Hospital for Sick Children (RBHSC). This is to ensure equity of access to specialist services for children across the region and to ensure that children residing in Belfast can access general paediatric services in their local hospital.

- 9.22 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 the North.
- 9.23 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 objective 5.

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

- 9.24 Specialised paediatric services are usually considered to be regionally (or nationally) commissioned services. They are often complex services with many associated interdependencies.
- 9.25 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.
- 9.26 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.
- 9.27 While the RBHSC is the regional children's hospital, this does not necessarily mean that all services have to be delivered centrally but that they should be co-ordinated regionally through a networked approach. This approach is currently being supported by the work of the HSC Board and Public Health Agency to co-ordinate 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

- region. An example of this is the creation in 2015 of an All-island Network Board to provide congenital cardiac services for the populations of Ireland, North and South.
- 9.28 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.
- 9.29 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 facilitates the integration of care closer to home, where appropriate.
- 9.30 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. 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 to deliver services locally wherever this can be done safely and sustainably.

Improving Access to and Quality of Paediatric/Neonatal Services

- 9.31 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, foetal medicine and perinatal mental health services.
- 9.32 The Department recommends that the Integrated Care Partnerships should consider the contribution that they could potentially make to strengthening patient access to paediatric services.

Objective 15

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.

- 9.33 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:
 - 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' 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.
- 9.34 An important element of the service specification 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.

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.

9.35 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.

Children with Complex Physical Needs

Objective 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 arrangements to facilitate the earlier discharge of children with complex health needs into their local community.

- 9.36 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.
- 9.37 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. Therefore, the HSC Board and Trusts working with the paediatric network should progress the work undertaken by the Regional Inter-agency Implementation Group for children with complex health needs and in particular put in place a "step-down" programme of care to facilitate and support 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.

Workforce development and training

Objective 18

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

- 9.38 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.
- 9.39 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.
- 9.40 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.
- 9.41 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 *General Paediatric Surgery and ENT Surgery* standards 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.

Objective 19

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

- 9.42 With the shift of services to the community 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.
- 9.43 As a result, the Department requires appropriate workforce planning to be implemented to ensure that staffing levels and competencies can safely provide for the needs of children and adolescents; this will be crucial to the success of the proposals in this Strategy.

Imaging and Diagnostics

Objective 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.

Objective 21

The proposed Paediatric Managed Clinical Network should prepare a business case to support the implementation of recommendations from the ongoing DoH Review of Imaging Services, which identify the future needs of paediatric radiology and related diagnostic services, when the recommendations have been finalised.

- 9.44 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 which undertake both paediatric and 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 sub-specialisation, and best practice would suggest that all paediatric radiological examinations be reported by paediatric trained radiologists.
- 9.45 Most hospitals 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 RBHSC 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.
- 9.46 Out-of-hours emergency radiology cover continues to prove difficult for some hospitals particularly during periods of leave. The DoH Review of Imaging Services has examined this issue and recommended that a regional network service model, including out of hours, should be developed and formalised. 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 developed by the regional Paediatric Clinical Network.
- 9.47 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.
- 9.48 In order to secure a whole system approach to the delivery of paediatric services the proposed regional Paediatric Network will include a paediatric imaging sub-group to support the safe delivery of paediatric imaging services across the region in line with the emerging DoH standards for imaging.

Information Communication and Technology (ICT)

Objective 22

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

- 9.49 The DHSSPS Information Communication and Technology Strategy (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 management, and also to improve patient safety when responsibility for an individual's care passes from one team or organisation to another.
- 9.50 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 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.
- 9.51 New or improved ICT is viewed as an enabling component of service change and service improvement initiatives. In view of this the Department requires that in taking forward

the implementation of the ICT Strategy the needs of paediatric services are included in each project, where appropriate.

Research

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

Theme 12

Robust Outcomes Data

Objective 23

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

9.53 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 within and beyond the region is readily available.

10. Working Together to Implement the Strategy

10.1 The Department will take the lead in taking forward the Implementation Plan to progress the objectives in the Strategy within the overall transformation of the Health and Social Care system as set out in 'Health and Wellbeing 2026: Delivering Together'.

The Department will work with the Health and Social Care Board (and its successor), the Public Health Agency, Health and Social Care Trusts, Local Commissioning Groups (LCGs), primary care practitioners, and other voluntary sector providers of paediatric care. Progress on the Implementation Plan will be monitored through new transformation accountability arrangements. Some of these objectives can be achieved relatively easily, others will take longer to achieve as they will require detailed planning. Implementation of the objectives will also be subject to available resources against the background of competing priorities for new investment across health and social care.

11. Equality Screening

11.1 Equality and Human Rights screening has been carried out and, at this time, it is considered that the introduction of the objectives in this Strategy will have no adverse impact on any of the groups mentioned in section 75 of the NI Act 1991.

Summary of Strategic Objectives

Objective 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.

Objective 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.

Objective 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.

Objective 4

A regional Managed Clinical Paediatric Network should be established to ensure equity of access to high-quality services across the North. The Network would include commissioners, providers, clinicians, social workers and patient representatives and should work closely with the voluntary and community sector. The Network should:

- a) include a surgical sub-group to support the safe delivery of paediatric surgical services in line with the Department's standards for general paediatric surgery;
- b) include a paediatric imaging sub-group to support the safe delivery of paediatric imaging services in line with the emerging DoH standards for imaging;

- c) include a paediatric palliative care subgroup to take forward the implementation of the Paediatric Palliative and End of Life Care Strategy;
- d) 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;
- e) consider a formal relationship between the paediatric network, the neonatal network and Integrated Care Partnerships in order to establish firm linkages; and,
- f) work with clinicians and academics to develop research resources.

Children (from birth up to 16th 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. In all cases, children and young people should have treatment and care delivered to them in an age-appropriate environment to meet their physical, emotional, social, spiritual, educational and psychological needs.

Objective 6

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.

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.

Objective 8

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)¹⁹
- 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.

Objective 9

Emergency Departments that accept children aged 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.

¹⁹ Maximising Nursing Skills in caring for children in Emergency Departments, RCN, 2010.

Emergency Departments that accept children aged 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.

Objective 11

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)²⁰ within four hours of admission and by a consultant within 24 hours of admission. This will be kept under review by the Managed Clinical Network (see Objective 4).

*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.

Objective 12

There should be continued progress towards implementation of the *General Paediatric Surgery* and *ENT standards* (DHSSPS, 2010). 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 surgeon for general paediatric surgery, in the local district general hospital, 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.

Objective 13

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 Royal Belfast Hospital for Sick Children (RBHSC). This is to ensure equity of access to specialist services for children across the region and to ensure that children residing in Belfast can access general paediatric services in their local hospital.

²⁰ Advanced nurse practitioner, staff grade or associate specialist doctor or Doctor in training at ST4 or higher.

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

Objective 15

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.

Objective 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.

Objective 17

The Health and Social Care Board, Public Health Agency and Health and Social Care Trusts working with the paediatric network should put in arrangements to facilitate the earlier discharge of children with complex health needs into their local community.

Objective 18

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

Objective 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.

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.

Objective 21

The proposed Paediatric Managed Clinical Network should prepare a business case to support the implementation of recommendations from the ongoing DOH Review of Imaging Services, which identify the future needs of paediatric radiology and related diagnostic services, when the recommendations have been finalised.

Objective 22

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

Objective 23

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

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 Acting Director of Secondary Care, DHSSPS (Chair January – May 2013)

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

Ms Zoe Boreland - former 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 – former 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 – former Senior Medical Officer, DHSSPS

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

Ms Sharon McCloskey - Care Services Manager, NI Hospice

Mr Jim McComish – former Regional Services Unit, DHSSPS

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

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

Ms Laura Smyth – former Hospital Information Branch, DHSSPS

Ms Hazel Winning - AHP Officer, DoH

Critical Experts

Dr Heather Payne - Senior Medical Officer, Welsh Government

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