

**Prospectus for
CHILDREN'S HEALTH SERVICES
Delivered in community settings**



British Association for
Community Child Health

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Purpose

This booklet informs commissioners, other providers and users about the components of child health services that may be provided in community and non-acute hospital-based settings¹ and provides suggestions for future developments

Introduction and document overview

This prospectus is a framework for paediatricians to use when engaging with commissioners and managers to describe and develop their services. It should be read in conjunction with *"Introducing the 'Family Friendly Framework': A whole systems approach to improve the commissioning services for children and families"* (BACCH, 2011). This prospectus is the first attempt to "capture" the work undertaken by community child health services and the intention is to update and improve the content over time. Suggestions for improvement would be welcome.

Compared to acute hospital-based services, which have relatively clear service boundaries and clinical pathways, Community child health services (CCHS) are often less well understood. In addition, there is considerable variation in how community based children's services are delivered in different parts of the UK. Certain conditions, for example, autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) assessments are provided by CCHS or by local Child and Adolescent Mental Health Services (CAMHS), often depending on the child's age, with variable joint working relationships. Similarly the management arrangements for community child health services range from being integrated into hospital foundation trusts, through to social enterprise structures and further integration with children's social care and other Local Authority children's services. It is therefore difficult to have one definitive framework, so this not a prescriptive document but it is intended as framework for adaption at a local level.

This prospectus aims to be inclusive and is not limited by current service configuration and structures. The services that are commonly provided by Community child health services are outlined in individual chapters. Each chapter has a similar structure and includes the main conditions covered by the service area, their prevalence and the service components that can be delivered in community settings. These aim to provide a common understanding, for clinicians, managers and commissioners, of the population needs and the service components required. Relevant references are quoted at the end of each chapter.

Care pathways should be in place for all conditions and a generic pathway would include prevention and early recognition, assessment and interventions for the three parts covering the initial, review and transition phases of the pathway covering those elements relevant to the condition, the impact on the child, the consequences for the family and wider community issues. This framework is used throughout the document in recommending service components for the various service areas.

¹ Some Community child health services are delivered within hospitals and some are managed by Hospital Trusts. The recommendations of this document are applicable to such services also.

Community child health services may not be the sole provider for a particular component in a pathway and therefore local commissioners will need to integrate all of the parts to achieve better outcomes. The key is that the local population needs and priorities are met, making best use of resources. From a family perspective it is essential that all the parts fit seamlessly together and that all the teams providing care work together well to create well integrated care that improves year on year.

There is a spreadsheet calculator associated with this document and is available on the BACCH website to help with assessing local service needs. It is a reckoner that calculates expected service demands from some of the commoner clinical conditions. This could be helpful to assess if individual services have the adequate resource to meet the expected demands.

In addition, BACCH is committed to developing a pathway approach to the deliver of services to children and young people(CYP) and their families. This is to include condition and pathway specific standards, measures and a process to improve services. We hope to deliver this in the next 12 months. Another document to be developed in the near future by BACCH is a set of 10 service standards for community child health services, and this aims to complement the 10 service standards for acute paediatric services developed by the Royal College of Paediatrics and Child Health (Facing the future, 2011).

The epidemiology of conditions in childhood is changing away from acute illness and injury, which is best managed in hospital settings, towards long-term conditions requiring a multiagency team, best delivered in community settings. The importance of developing a competent team with the right skill-mix that works well with others to provide “a team around the family” cannot be understated. It is hoped that the framework and examples offered here, even though they may not represent every service exactly, will serve to provide a basis for clinicians, service managers and commissioners to reflect and improve local configurations, practice and quality.

It is intended that these general descriptions should be applicable across all UK nations and relevant references reflecting the differences between the four nations are included.



Simon Lenton
BACCH Chair

October 2012

Philosophy and Principles of Good Practice (United Nation Convention on the Rights of the Child - UNCRC)

Four philosophical values underpin the service offered to children and families:-

1. Children have **rights** which must be respected and promoted. The service will adhere to the 54 articles in the UNCRC, for example rights to a safe and healthy environment, good nutrition and a secure and loving family life. Article 24 covers access to quality health services.
2. Children should be seen as **children first**, rather than as a disease process or problem, recognising their changing needs and abilities in the context of their growth and development – physical, emotional and social, as they become older.
3. Parents and children should **actively participate** in the care they receive.
4. Each child is a **unique** individual. Their special abilities and needs, and their racial, linguistic, religious and cultural backgrounds must be respected.

To ensure the service is efficient, fair and responsive, the following service principles of good practice should also apply:

1. Services should be both **accessible** and **family friendly**. They should however be the best for that individual child with that particular condition even if it means the child has to travel to reach the specialist in that field; in these cases care should be delivered within a **network**, ensuring the child has access to the services and expert opinion they need.
2. Services should **promote and protect** the health of children and families and advocate for their needs.
3. Services should be **well co-ordinated** between all the agencies and disciplines involved and provide **continuity** over a period of time. **Pathways of care** should be agreed and owned by all stakeholders, including children and families, explicit and clearly written so that access to services is transparent.
4. Services should be **evaluated regularly** to ensure they are meeting the most recent evidence and continue to adhere to the current evidence based guidelines, taking into account the evolving needs of the child population and their families. **Measures that matter should be chosen wisely so that they stimulate reflection, learning and improvement and the collection of data and analysis is not an unnecessary burden.**

5. Services should be delivered by **competent clinicians** who are appropriately trained and **regularly appraised** to ensure they maintain their skills and fulfil **continuing professional development requirements** as determined by their professional regulators.
6. Services should offer value for money, provision being clinically **effective, equitable and cost-efficient**. Services should be commissioned over a realistic time frame to allow development of new services and the sustainability of established services. Services should then work **within the available resources** taking account of economic, social, political and environmental factors.
7. Children should be seen and assessed in suitable accommodation whether at a health centre, children's centre, local hospital, school and where necessary, at home². The standards defined by the RCPCH are applicable to any paediatric consultation in any location.
8. Children with complex problems should receive care from a multidisciplinary team who deliver a range of evidence-based interventions. In providing the best possible overall service **collaborative working in the interests of children** has a higher value than the competitive interests of different organisations.

² This may mean particular accommodation to the needs of certain groups of children e.g. quiet space for children with autism; adolescent facilities etc.

Child Public Health

Principles of Child Public Health and current priorities

Child Public Health is largely concerned with improving the health of children through population or community based interventions. The primary focus is on promotion of health, protection from harm and the prevention of disease/problems. Public Health is also concerned about achieving maximum health gain for the resources available, by improving access to excellent quality health services and the reduction of inequalities in health outcomes.

Child Public Health takes a life course epidemiological approach which acknowledges that health and well-being as a child, young person and adult depends on a range of factors preconception, during pregnancy and in the early years. Most of the major determinants are social, economic and environmental. Public health practice seeks to improve health through promoting these positive determinants, and by protecting infants and children from adverse factors. This twin health promotion and health protection approach is applicable throughout life. Therefore, Child Public Health takes a "whole system" approach to improving the life chances of both children and families by creating alignment and synergy between the key stakeholders, within public private and voluntary sectors, that influence the health and well-being of children and families at all life stages.

Current priorities of child public health activity are:

- The development of programmes to address key issues such as obesity and parenting
- Improving access to health services especially for the most vulnerable families
- Reducing unnecessary variations in the outcomes of services.
- Improving priority setting and the allocation of resources in times of austerity.

Service components delivered by community child health services

Service Delivery

Child health services in the community will discharge child public health responsibilities by:

- Working with colleagues in public health by providing operational support and clinical advice – at a local level to identify need and prioritise local initiatives; building on their experience of working with vulnerable families, in bringing narrative and local understanding to public health advocacy and community development; whilst also developing appropriate epidemiological data collection;
- Working with other partners such as education and social care – to deliver local initiatives aimed at the social determinants of health
- Leading on specific programmes which may include:
 - Immunisation³

³ Many CHS continues to provide immunisation services, but as the lead has moved into public health/local authority, the role of the provider unit as well as where accountability sits varies.

- National screening and health surveillance programmes
- Injury prevention
- Obesity

In England and Wales, the new arrangements for commissioning, delivering and regulating child public health as directed by the Health and Social Care Act (2012) are being rolled out, with the prospect that some functions will be undertaken by Public Health England, some by local authorities and others within the health service. Scotland and Northern Ireland have different public health commissioning arrangements. In Scotland, health services are commissioned by 14 Health Boards. In Northern Ireland, the Health and Social Care Board, having merged with the Public Health Agency since 2007, commissions services for 5 local health trusts.

Service components

(a) Neonatal Blood Spot Screening in line with national and local policies

Under a strategy set by Public Health, the Community Child Health Department may be responsible for operational matters such as:

- running call/recall system to ensure complete coverage and smooth running of programme;
- following up abnormal results with appropriate communication with parents/carers and involved clinicians;
- overall service co-ordination;
- Standard setting, measurement and improvement.

(b) Newborn hearing screening programme:

This programme is usually led by the local Audiology Service. Please see the Audiology chapter in this document for more information (Pages 33-34).

(c) Healthy Child Programmes (HCP)

The Community Child Health Service is responsible for:

- providing clinical leadership alongside a public health colleague as outlined in the Healthy Child Programme (HCP);
- negotiating screening and surveillance policy with commissioners as guided by the current evidence based recommendations for children and young people aged 0-19 years;
- implementing screening tests from birth;
- Personal Child Health Records: issued to every newborn child so that information on the birth and neonatal examination may be entered;
- training of GPs, health visitors and other staff who contribute to the programme;
- data collection and analysis for performance management of screening programmes;
- feedback of relevant information to primary care teams;
- medical assessment of some children referred from screening/surveillance tests.

(d) Childhood Immunisations

Much of this is delivered by Primary Care and School Nurses. Community Child Health Service staff e.g. Nurse Practitioners may give the following immunisations:

- BCG to children in high risk groups
- Adolescent diphtheria tetanus polio in school settings
- Hepatitis B to groups at risk
- HPV
- Influenza to high risk groups
- Immunisation campaigns e.g. MMR catch-up

Those families with specific concerns or withholding consent for immunisation may be offered outpatient consultation for specialist advice and support with a view to successfully immunising their children.

Other primary immunisations are given by the GP and practice nurse but the Community Child Health Department may be responsible for:

- Maintaining clinical leadership at operational level;
- Maintaining population database for children locally resident;
- Maintenance of computerised immunisation records;
- Establishing IT communication with GP (or primary care) held immunisation database to facilitate accurate immunisation recording
- Sending parents information about immunisation;
- Feeding back uptake rates to primary care teams;
- Quarterly immunisation newsletter;
- Maintaining an immunisation telephone hotline;
- Targeting and follow-up of vulnerable families who are un-immunised;
- Training staff from various professional backgrounds.

(e) Targeted Interventions

- Child health is not distributed equally throughout society so some vulnerable groups may require targeted programmes of care such as the Family Nurse Partnership Programme or specific injury prevention programmes to reduce future morbidity.
- Child health services in partnership with other health service providers should have the capacity to respond to ad hoc national and local initiatives, including addressing outbreaks of diseases.

(f) Data collection of health needs and trends: to inform national and local commissioning.

Potential Changes, Developments and Research Opportunities

Innovative programmes should be developed in partnership with local clinical commissioning groups, public health departments and local authorities; for example:

- injury prevention programmes;

- obesity reduction strategies
- further targeted health promotion programmes, for example reducing unwanted pregnancies;
- reducing rates of smoking among adolescents;
- increasing access to parenting programmes;
- improving access to SEAL programmes;
- improving access to Family Nurse Partnership programmes.

References

1. DH (2009) Healthy Child Programme: pregnancy and the first five years of life
2. DH (2009) Healthy Child Programme: from 5-19 Years
3. 'Fair Society, Healthy Lives', The Marmot Review 2010

Vulnerable children and families: Safeguarding, Child Protection, Looked After Children, Adoption and Fostering

Description of clinical concerns or groups of conditions covered

The general aims of the service are to prevent, identify, assess and support children and vulnerable families who experience health difficulties due to adverse circumstances, poor mental health, social problems, substance misuse and to work closely with other relevant agencies, in particular Children and Young People's Services (CYPS) and the police/criminal justice teams.

The main components of this service area are:

- Safeguarding – supporting vulnerable families
- Child protection
- Looked after children
- Adoption and fostering

Safeguarding – supporting vulnerable families

In the course of their everyday clinical work clinicians will recognise that adverse social conditions may affect the health and well-being of children and interfere with the best management of their medical conditions. It is important for them to recognise and acknowledge these concerns with parents and then make appropriate referrals to other professional groups or agencies in order to access interventions to address these concerns.

Some individuals or families are known to have poor health outcomes, for example, immigrants, mental health problems, teenage mothers; and it is important that these vulnerable families access support and evidence-based interventions in order to tackle the underlying determinants or lifestyles that may impede the health and well-being of their children.

Child Protection

In any given area paediatricians and their teams need to have sufficient expertise to:

1. provide advice to other professional groups who may have concerns that a child is being abused
2. participate in multi-agency child protection strategy discussions and other meetings,
3. assess and give an opinion on children and young people where there is a suspicion of maltreatment or alleging maltreatment 24/7; this will include children with severe injuries on specialist wards or in Paediatric Intensive Care Units (PICUs);
4. provide or understand when and how to refer to a specialist service over wider geographical network that has the required staff and facilities to assess children and young people presenting with complex safeguarding problems including acute and historic sexual abuse e.g. this may include joint working with Forensic Physicians at a Sexual Assault Referral Centre (SARC);

5. provide outpatient paediatric assessments and follow up for vulnerable children referred by health professionals, social care, or other agencies;
6. provide reports and statements for social services and the police;
7. attend child protection conferences or court proceedings as required.
8. provide teaching, audit and where possible, research in the area of safeguarding.

Senior doctors undertake the role of Designated Doctors and sit on the Local Safeguarding Children's Board (Child Protection Committees) and its sub-committees to develop good practice, review standards and implement guidance. Every Health Trust/organisation also requires a Named Doctor, Nurse (and Midwife if Obstetric Unit). The model job descriptions for both Named and Designated Doctors are found on the RCPCH website. Named and Designated professionals ensure that training is provided for NHS and non-NHS professionals at all levels of the child protection process.

Working Together (2003) recommends that health care workers should have access to child protection advice 24/7. In some areas, there is an on-call rota amongst to fulfil this requirement. In some areas paediatricians participate in on-call rotas to provide forensic examinations for CYP who are referred to SARCs.

Looked after children

Looked after children (LAC) are defined by legal terms:

- In England and Wales, "looked after child" has the meaning in section 22(1) of the Children Act 1989 (c), extended to include a child accommodated by a local authority under section 17 of that Act
- In Northern Ireland, "looked after child" means a child accommodated under Part 4 of the Children (Northern Ireland) Order 1995
- In Scotland, "looked after and accommodated child" means a child who is:- (a) both looked after, and provided with or placed in accommodation, by a local authority within the meaning of those expressions in Part 2 of the Children (Scotland) Act 1995 (b), or (b) accommodated by a local authority under section 22 of that Act

LAC have a disproportionate number of learning, mental and behaviour problems and are frequently difficult to assess as key information may be held in different agencies and locations across the UK. There is often no parent who can collate this information to give a coherent view of the child's difficulties and advocate on their behalf. 45% of LAC are assessed as having a mental health disorder, increasing to 72% for those in residential care. Conduct disorder was most common for all LAC (37%), with 12% having emotional disorders such as anxiety and depression. A robust system is required to ensure that routine and specific health care is available for such children on a consistent basis.

Community child health services are involved with the statutory Initial and Review Health Assessments of children who are Looked After. The Designated Doctor for Looked after Children (usually a senior Community Paediatrician) provides strategic advice to Health and the Local Authority commissioners and this has been a statutory requirement since 2009.

Adoption and Fostering

Children may not be able to live with their birth parents for a variety of reasons. Many have suffered abuse or neglect, and a significant number have emotional, behavioural or physical disabilities. Many have missed out on universal services such as immunisation or dental care. Medical advice to the Adoption Agency is needed by law and is provided through a Consultant/Associate Specialist who is the Medical Adviser to the Adoption Panel.

Incidence/Prevalence

Using England as an example:

- England has a population of approx 11 million children (up to 19th birthday)
- 1 in 18 children are referred to social care for CYP every year (approx 55 referrals per 1000 child population)
- There were 65520 "Looked after" children in England (child population 11 million) on 31st March 2011 i.e. approx 6 per 1000 children in England are in the care of the local authorities.
- Approximately 3 "Looked after" children per 10000 are adopted every year.
- 1 in 300 children are subject to a child protection plan (3.3 per 1000) (requiring attendance by a health professional to at least 3 case conferences per year).

Service components delivered by community child health services

Child Protection

- a) Participation in strategy discussions with Social Care and Police
- b) Paediatric assessment of children in whom maltreatment is suspected
- c) Provision of reports and statements for Social Care, Police and Courts
- d) Provision of clinical advice at Child Protection Case Conferences
- e) Provision of clinical evidence and opinion at Court as required
- f) Peer review meetings to ensure uniform standards of practice and reports in safeguarding
- g) Designated Doctor for Safeguarding is responsible to health commissioners and provides strategic advice to commissioners and Local Authority/LSCB, advises commissioners on performance indicators/quality review of safeguarding, and engages in training. A model job description has been drawn up by RCPCH.
- h) Named Doctor for Safeguarding is responsible to a health Trust and works with Designated Doctor, advises health Trust re national and LSCB safeguarding strategies, Trust policies, training, Serious Case Reviews, and supports implementation of recommendations and monitoring/quality review. A model job description has been drawn up by RCPCH.

LAC, Adoption and Fostering

- i) Initial and review health assessments of Children Looked After, ongoing care as indicated. Some assessments may be undertaken by nurses or GPs. The Designated Doctor for LAC provides additional advice when necessary.
- j) Identification of emotional and mental health problems and referral to dedicated CAMHS service as appropriate.
- k) Medical Adviser for Adoption provides clinical advice to the Adoption Panel and information to prospective adoptive parents on children's medical needs. Model job descriptions have been drawn up by BAAF.

The role of Community Paediatricians in interventions for vulnerable children

In addition to providing medical advice on vulnerable children for the statutory services, Community Paediatricians also contribute to improving outcomes. This includes:

1. undertaking holistic assessments of children and young people referred to their service, to allow identification of risk factors which may prevent them from achieving their potential unless appropriate support and interventions are implemented;
2. have appropriate knowledge of local services for vulnerable children and families including referral processes and criteria;
3. engage in the early support services and interventions (including involvement with Common Assessment Framework) for children and young people recognised as "in need" of additional services;
4. engage with other multi-agency professionals including the Voluntary Sector in the development and delivery of local services to support vulnerable children and families.

Potential Changes, Developments and Research Opportunities

- Re-investment of services from post abuse to pre-abuse using 'hazards to health' approach.
- Improved assessment using structured decision-making (SDM) methodologies.
- Alternatives to "routine medicals" for adolescents in the care system to improve their engagement

References

1. Working together to safeguard children; March 2010
2. Ford T, Vostanis P, Meltzer H, Goodman R (2007) Psychiatric disorder among British children looked after by local authorities: comparison with children living in private households. *British Journal of Psychiatry* 190:319-25
3. RCPCH (2008): Model job description for Designated Doctor for Child Protection
4. RCPCH (2008): Model job description for Named Doctor for Child Protection
5. BAAF (2008): Model job descriptions and competences for medical advisors in adoption and fostering

Child Death

Description of clinical concerns or groups of conditions covered

The overall purpose of the Child Death Review Process is to understand why children die and put in place interventions to protect other children and prevent future deaths. This is statutory requirement as outlined in the chapter 7 of "Working Together" (2003).

Incidence/Prevalence

- Sudden infant death syndrome (SIDS): 0.4 per 1000 live birth
- About 600 babies die suddenly every year in the UK (0.8 per 1000 babies under 1 year of age)
- Child death reviews completed by Child Death Overview Panels (CDOPs) in England per year since 2010: 4000 (0.3 to 0.4 per 1000 child population under 18)

Service components delivered by community child health services

There are two interrelated processes and Paediatricians will be involved in one or both:

- a) A "Rapid Response Team (RRT)": A group of key professionals who come together for the purpose of enquiring into and evaluating the cause of death where the death of an individual child is "unexpected".
- b) A Child Death Overview Panel (CDOP): The panel is responsible for reviewing information on all child deaths ("expected" and "unexpected" under the age of 18 years) and is accountable to the Local Safeguarding Children Board.

Rapid Response Team

Paediatrician's role in the RRT:

1. Detailed history, examination and immediate investigative sampling
2. Liaise with other professionals to visit the place of death and interview carers within twenty four hours of death and prepare report for pathologist.
3. Chairing an initial information sharing meeting with all other relevant professionals and submission of report to the Coroner.
4. To convene a multi-agency discussion (usually by phone) shortly after the results of initial Post-mortem report are available to explore any other concerns and to keep the family and other professionals informed.
5. To convene and chair a Local Case Review meeting within three to four months of death to discuss final Post mortem report findings, prepare a final report for submission to CDOP and arrange feedback to the family.
6. In addition to this the paediatrician is expected to comply with any instruction from the coroner including additional visits, reports and attendance at the inquest.

For the "expected" deaths a discussion would take place amongst relevant professionals and a report to be submitted by the Paediatrician looking after the child to the CDOP.

Child Death Overview Panel

The Child Death Overview Panel discusses all the deaths of children (expected and unexpected) would meet at least four times a year and a paediatrician is a core member. The responsibilities include reading the reports beforehand, contributing to the discussion and follow on any action from the analysis.

Working Together specifies that each Primary Care Trust⁴ should have access to a Paediatrician with responsibilities for advising on child death review processes (designated paediatrician for unexpected deaths in childhood).

References:

1. Working together to safeguard children; March 2010
2. West Midlands best practice multi agency SUDC protocol
3. RCPCH guidance on Child Death Review processes (2008)

⁴ Or in a locality of comparable size within commissioning organisations post Health and Social Care Act 2012, or in non-English nations

Short Term General Paediatric Conditions

Definition

Short term conditions are those that resolve in a short period of time (generally <6 months) with or without medical interventions

Description of clinical concerns or groups of conditions covered

Depending on local service configuration and pathways, the contribution by community child health services in this area is variable. Children are prone to short term medical conditions of varying severity, as well as injuries. Recent UK based studies from attendance to Emergency Departments showed that six medical presentations, mostly with a minor, self-limiting underlying cause, accounted for 83 per cent of attendances:

- Breathing difficulties
- Fever
- Fits
- Diarrhoea and vomiting
- Rash
- Abdominal pain (including those with a surgical aetiology but presenting to non-surgical urgent care services initially.)

Apart from medical conditions, children and young people are prone to accidents. Large number of CYP attend urgent care centres and emergency departments with injuries. Whereas the majority have resulted from accidents, some are of intentional origin.

In addition, there are a number of relatively less common short term conditions such as reflux, constipation, UTI or orthopaedic problems where primary care professionals seek a second opinion on diagnosis or treatment. In parts of the UK, Community Paediatricians provide this opinion in community settings. It is important that care pathways are in place in conjunction with hospital services and primary care to ensure clarity of referral for assessment, further investigation and management of these children. A single point of access/entry for general referrals is preferred, so that children can be seen promptly by the most appropriate professional in the most appropriate setting. For example, it may be better for children to be seen out of hospital if they are not acutely ill and not in need of extensive investigation, provided that community based clinicians have the required competences and work within an appropriate service model.

It is important to remember that children with long term conditions are vulnerable to short term conditions just like any children, and indeed are more vulnerable to some of these conditions as a result of their underlying condition e.g. neurological impairment, breathing difficulties or organ failure. Some children presenting with short term conditions or injuries may be victims of maltreatment.

Incidence/prevalence:

Parents and carers will often manage their children's short term illnesses themselves without accessing health service formally. Children represent about 25% of a general practice population and are about 40% of workload of the primary care team. Approximately 3.5 million children under 16 attend emergency departments in the UK each year. This equates to around 28% of the child population and children usually constitute 25% to 30% of all attendances to emergency departments. Almost 90% of the children attending an emergency department will be seen and discharged without any involvement of in-patient services.

Service components delivered by community child health services

The main providers in this area are General Practice, Urgent Care Centres, Emergency Departments, Ambulatory Paediatric Services and Paediatric Inpatient Units. Depending on local service configuration and pathways, the contribution by community child health services is variable, but often less recognised and not always with formal commissioning or service level agreements. Examples of involvement by Community Paediatricians include:

- a) Joint appointment between community and hospital services, to provide hospital-based care for children.
- b) Community based consultation for children with short term conditions which may be in partnership and co-located with Primary Care.
- c) Community based consultation or advice for patients known to community services who have developed short term complications related to their underlying conditions
- d) Consultation for children with long term conditions or neuro-disabilities admitted to hospitals, including those in PICUs, as many will be known to CCHS already. This may include decisions on end of life care and discharge planning.
- e) Direct clinical or advisory role when there are safeguarding concerns, which includes advice to Urgent Care Centres or Emergency Departments
- f) Consultative role to Social Care and Education Services when appropriate

It is important to deploy community child health resources efficiently by focussing on patients who are most likely to benefit from their specialist skills. For example, reducing attendance at Emergency Department by the general paediatric population is best achieved by Primary Care and Urgent Care Centres, whereas reducing the need to access hospital based paediatric services by children with long term conditions or neurodisability is a more appropriate role for Community Paediatricians.

Potential improvements/developments

- Closer working with general paediatric providers at all levels, reviewing and establishing joint pathways as appropriate
- Strengthening the capacity for community child health services to contribute at every stage of the patient journey during an acute or short term episode, particularly for those with neurodisabilities. Strengthening community paediatric nursing services should be considered strongly.
- Embedding community child health expertise in the development of community based specialist services ('Polyclinics' or 'Polysystem' equivalent)

- Support and education of General Practice staff, and perhaps training some GPs to becoming experts in child neurodisability to complement Community Paediatricians

References

1. Intercollegiate Committee (2007), Services for children in emergency departments, RCPCH
2. Children and Young People's Care in North East London: Proposal to Support Decision Making. Health for North East London Programme (2010)
3. Paediatric Emergency Services: Case for Change. London Health Programmes (2012) [Will be published shortly]
4. Armon, K. et al., 'Audit: Determining the Common Medical Presenting Problems to an A&E Department' in Arch. Dis. Child (2001) p. 391
5. Krauss B., Harakal T., Fleisher G., 'The spectrum and frequency of illness presenting to a paediatric emergency department' in *Pediatr Emerg Care* (1991) 7:67–71
6. Stewart M., Werneke U., MacFaul R. et al., 'Medical and social factors associated with the admission and discharge of acutely ill children' in *Arch Dis Child* (1998) 79:219–24

Children with neurodevelopmental disorders, neurodisabilities and special educational needs (SEN)

Description of clinical concerns or groups of conditions covered

It is increasingly recognised that children benefit from care being provided within their community as close to home as possible. Much of the work of Community Child Health Services consists of the identification, assessment, investigation and support of children with long term neurodevelopmental disorders and neurodisabilities, often working in a multidisciplinary team, liaising with primary and acute health care, networked with a range of tertiary care, and other agencies as appropriate. Many children and young people within this group have complex medical conditions. In addition to their primary neurological condition, many have a variety of secondary associated problems requiring medical management, e.g. gastro-oesophageal reflux, seizures, constipation.

Children with a wide range of conditions are included within this service area:

- physical disability - e.g. cerebral palsy, muscular dystrophy, spina bifida;
- intellectual disability – learning difficulties (mild, moderate, severe and complex), in relation to investigation of aetiology and support of co-morbidities;
- neurodevelopmental disorders⁵ e.g. Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, Developmental Coordination Disorder, language and communication disorders, Tourette syndrome.
- impairments of special senses – hearing (see Audiology Chapter Pages 33-34), and vision impairment;
- acquired disorders e.g. brain injury due to trauma or illness.

Special Educational Needs (SEN): the legal framework

In the UK, there is legislation that determines the provision for CYP with special educational needs (SEN). Within this, there are specific definitions for SEN, and legal requirements for identification, assessment and provisions for these CYP.

- The procedures for SEN in England and Wales were set in the Education Act 1996 (Part 4). The definition of SEN was amended in the Special Educational Needs and Disability Bill of 2001. There are likely to be further changes in the near future, following publication of the Green Paper 'Support and aspiration: A new approach to special educational needs and disability' (Consultation: 2011; Progress and next steps: 2012).
- In Scotland, SEN is provided under The Education (Additional Support for Learning) (Scotland) Act 2004. This Act also broadens to "additional support needs" and includes factors affecting a child's learning such as bullying, bereavement, family being in care or being a teenage parent.

⁵ Children with neurodevelopmental conditions often present with predominantly behavioural concerns and may be referred to CAMHS initially. Close working between CCHS and CAMHS is particularly important here. Please see also chapter on 'Children with mental health and behaviour problems' Pages 24-27.

- In Northern Ireland, The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO) which came into operation on 1 September 2005 increases the rights of children with special educational needs (SEN) to attend mainstream schools and introduces disability discrimination laws for the whole education system in Northern Ireland.

Many CYP with neurodevelopmental conditions and neurodisabilities, as well as those with long term medical conditions, behaviour and mental health problems, are eligible for the provisions within these legislations. Also, such provisions are not exclusive to CYP known to CCHS. Others with less obvious health related conditions may also be subject of SEN provisions e.g. some CYP with specific learning difficulties.

Within these legislations, state funded health organisations are specifically required to notify to education authorities CYP who may have SEN. They are also required to provide medical advice for CYP undergoing statutory assessment for SEN. CCHS are the usual lead service in fulfilling these statutory requirements, which include strict timescales in responding to request for reports.

Incidence/prevalence:

- 4% of the population have severe disabilities.
- Up to 20% will have some disability at some time.
- 2.8% of children in England and Wales receive provisions under SEN legislation.
- The prevalence of the more important neurodevelopmental and neurodisability conditions are:
 - Cerebral Palsy: between 2 to 3 per 1000
 - Autism spectrum disorder: about 1 in 100
 - Attention deficit hyperactivity disorder: about 1 in 100
 - Learning disabilities: between 2 to 3 per 100 children were estimated to have a learning disability by Department of Health in 2010
 - Congenital severe to profound sensorineural deafness: 1 to 2 per 1000
 - The prevalence of blindness in children is estimated to be between 3.4 - 4.0/10,000, and partial sightedness between 5.4 and 8.7/ 10,000
 - Acquired brain injury: 20 to 30 per 10,000 children admitted to hospital per year

Service components delivered by community child health services

Service Delivery

- A 'child and family centred' model of service delivery is paramount
- Multidisciplinary teams with specific training in the neurodevelopmental disorders, their differential diagnosis, common co-existing conditions and provision of intervention strategies.
- Close working with health co-providers, especially local hospital paediatric services and CAMHS
- Close working with Education and Social Care services
- Key worker role/Case coordinator for complex disabilities

- Rehabilitation team for acquired disorders, including rapid response from local services and liaison with tertiary services and working with their outreach teams.
- Transition planning

Service objectives

- Early diagnosis and interventions, contributing positively to the reduction in late and potentially more intense treatment of presenting conditions
- To ensure effective multidisciplinary and interagency working, with holistic approach to assessment and management, taking into account the needs of the family members as well as the child's, and transition planning is managed in a timely manner
- Children and young people who are living with a Long Term Condition (LTC) and, or disability are proactively managed and as a direct result there is prevention of unnecessary exacerbation of symptoms and in turn reduction in avoidable acute hospital admissions
- The service aims to reduce the impact of disability on family members through appropriate coordinated care and support, anticipation and recognition of problems and timely interventions including short breaks

Service components

a) Prevention and early recognition:

- preventative initiatives in line with public health strategy and local service model and priorities e.g. immunisation, folate supplementation, injury prevention, genetic counselling for families at high risk;
- follow up of high risk infants from NICU;
- transparent access to all with a concern about a developmental problem whether from the Healthy Child programme, opportunistic holistic care; the education service or parents;
- care pathways in place for new concerns both developmental and acquired and for co-existing problems.

b) Assessment:

- diagnosis, aetiological investigation and management of above conditions in a coordinated way and in conjunction with primary, secondary and tertiary services;
- evidence based and standardised measures of assessment where possible;
- Skilled trained neurodisability multi-professional teams integrated with education and social care to develop a single care plan, and overseeing its implementation;
- Personalised family focussed care, taking a lifetime approach.

c) Management:

- information and explanation for parents;
- appropriate medical, physical and mental health treatment available recognising the increased physical, emotional, behavioural and functional impairments in those with disability ;
- specific therapies including rehabilitation after an acute event;
- referral for aids or appliances;

- networking with tertiary care and other specialist services, working collaboratively to provide integrated care;
- co-ordination of the multidisciplinary and multiagency team;
- advice to Social Care and / or Education Departments;
- ensuring a keyworker approach is in operation for families with children with disabilities.

d) Co-ordination of care and support:

- servicing and chairing multidisciplinary meetings e.g. early participation in education and social service reviews.

Potential Changes, Developments and Research Opportunities

1. Development of community children's nursing teams
2. Development of the use of computerised special needs registers shared across agencies.
3. Enhanced parental information systems
4. Improved coordination between services e.g. Development of multiagency wheelchair service with one budget for all equipment at home and at school.
5. More joint provisions between Community, Hospital and CAMHS

References

1. DfES (2007) Aiming High for Disabled Children: Better support for families
2. DH (2007) Mental Health Act
3. DH (2007) Children's health, our future: A review of progress against the NSF for Children and Young People and Maternity Services -2004
4. DH (2004) National Service Framework for Children, Young People and Maternity Services
5. HM Government (2004) The Children Act 2004
6. Woodside, Rosenbaum, King, & King, Centre for Childhood Disability Research, McMaster University (1998) Measure of Process of Care for Service Providers (MOPC – SP)
7. Report of the CYP outcomes forum summer 2012
8. Hawley CA, Ward AB, Long J et al. Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: A population based study. *Injury: International Journal of the Care of the Injured* 2003; 34:256–260.
9. DfE Green Papers (2011 & 2012). Support and aspiration: A new approach to special educational needs and disability. Consultation, progress and next steps.
10. Education Act (1996)
11. SEN and Disability Bill (2001)
12. The Education (Additional Support for Learning) (Scotland) Act 2004
13. The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)

Children with mental health and behaviour problems

Description of clinical concerns or groups of conditions covered

There is a wide range of emotional and behavioural problems which present during childhood and adolescence requiring particular services which may be organised through CCHS, CAMHS or both.

Children who have a physical illness are 2 to 5 times as likely to develop an emotional or mental health problem. Children with neurodevelopmental disorders have an increased likelihood of mental health and behaviour disorders and problems, as do 'Looked After Children'. Both groups may require particular expertise. Behaviour and mental health problems are commonly encountered in families with psychosocial risk but not exclusively so. Diagnostic and evidence based therapeutic services are required.

Community Child Health Services may see children with the conditions in the table below. However, these conditions are also seen by CAMHS teams, and there is significant overlap and variability of service provision around the country. Local commissioning must ensure there are local care pathways for mental health and behavioural problems, that include clarity about services from Paediatrics/CAMHS/Education/Social Care and the voluntary sector.

<u>Broad group</u>	<u>Examples</u>
Emotional disorders	- depression, anxiety, phobias
Behavioural disorders in pre-schoolers	- food selectivity; sleep disorders; tantrums
Eating disorders	- anorexia, bulimia, obesity
Conduct disorders	- stealing, truancy, delinquency
Self harm and substance misuse	
Psychosis	

In addition, children with neurodevelopmental disorders⁶ such as ADHD, Tourette's Syndrome, learning difficulties, autism spectrum disorder, selective mutism etc. often present with behaviour concerns rather than as an obvious developmental disorder. Referrals may be made to either CCHS or CAMHS. Joint pathways and close collaboration is particularly important here to avoid families and children being passed between services with little progress made.

⁶ Recommendations for neurodevelopmental disorders are described in more detail in the chapter entitled 'Children with neurodevelopmental disorders & neurodisabilities' (Pages 20-23)

Incidence/prevalence

- 1 in 10 children and young people aged 5 - 16 suffer from a diagnosable mental health disorder - that is around three children in every class.
- Between 1 in every 12 and 1 in 15 children and young people deliberately self-harm and around 25,000 are admitted to hospital every year due to the severity of their injuries.
- More than half of all adults with mental health problems were diagnosed in childhood. Less than half were treated appropriately at the time.
- Nearly 80,000 children and young people suffer from severe depression.
- Over 8,000 children aged under 10 years old suffer from severe depression.
- 60% of children in care have a mental health disorder - these are some of the most vulnerable people in our society.
- 95% of imprisoned young offenders have a mental health disorder. Many of them are struggling with more than one disorder.

Service components delivered by community child health services

A collaborative approach with CAMHS is essential in delivering service to children and young people with mental health concerns. CCHS will often lead on services for preschool children with behavioural difficulties in the context of confirmed or undiagnosed developmental difficulties, but also often have little mental health support e.g. clinical psychology. In many services they will also assess and treat older children and adolescents with co-morbid developmental and behavioural difficulties, but not usually emotional or psychiatric disorders.

Community Paediatricians have a different set of competences from CAMHS Professionals and it is important to make use of their skills efficiently e.g. it is inappropriate for them to cover for inadequately provided CAMHS. This will lead to potentially unsafe practice and distract Community Paediatricians from more appropriate clinical work.

a) Prevention and early recognition:

- Preventative initiatives in line with public health strategy and local service models and priorities e.g. health education, referral to parenting programmes.
- transparent access to all with a concern about a mental health problem whether from the Healthy Child programme, opportunistic holistic care, the education service or parents;
- care pathways in place with partner health services and other agencies.

b) Assessment:

- initial assessment, sometimes in cooperation with CAMHS under joint pathways;
- evidence based and standardised measures of assessment where possible;
- Skilled trained CCHS based multidisciplinary teams.

c) Management:

- information and explanation for parents;
- appropriate medical, and mental health treatment available, appropriate to the skills of the CCHS clinicians and local service model;
- referral to CAMHS and other specialist services, working collaboratively to provide integrated care;
- advice to Social Care and Education Departments.

d) Co-ordination of care and support:

- servicing and chairing multidisciplinary meetings e.g. early participation in education and social service reviews.

Prompt recognition and identification of these problems may make them easier to treat successfully. Understanding their multi-factorial origins through thorough assessment may help generate a number of different interventions.

Children with behaviour problems can be seen by members of the Community Child Health Service in a variety of settings. Clear criteria for referral are required, but will be focussed on the assessment of medical and developmental causes of mental health difficulties. Providing effective treatment and advice may require liaison with CAMHS Departments and other services, particularly in Education.

CAMHS teams see a relatively small number of families with more severe or complex problems. They may offer support and supervision to paediatricians and to other professions who work with families who have less severe problems or those who do not wish to attend their service.

Potential Changes, Developments and Research Opportunities

- Multi-agency pathways for assessment and management of children with emotional and behavioural problems.
- Continued programme of training for primary care teams in the management of common behaviour problems.
- Provision of joint clinics between Child and Adolescent Mental Health Services and Community Child Health for children with medical and psychological problems such as soiling.
- Multi-agency pathways for assessment and management of children with autistic spectrum disorders.
- Provision of evidence based programs e.g. parenting programmes for pre-school children with behaviour problems.
- Emotional resilience programmes in schools e.g. FRIENDS programme.

References

1. DH (2007) Mental Health Act
2. Green, H., McGinnity, A., Meltzer, H., et al. (2005). Mental health of children and young people in Great Britain 2004. London: Palgrave.

3. Mental Health Foundation (2006). Truth hurts: report of the National Inquiry into self-harm among young people. London: Mental Health Foundation
4. Fox, C. & Hawton, K. (2004). Deliberate self-harm in adolescence. London: Jessica Kingsley Publishers.
5. Kim-Cohen, J., Caspi, A., Moffitt, TE., et al (2003): Prior juvenile diagnoses in adults with mental disorder. Archives of general psychiatry, Vol 60, pp.709-717
6. Office for National Statistics (2004). Census 2001: national report for England and Wales. London: Office for National Statistics.
7. Department for Children, Schools and Families (2009c). Youth cohort study and longitudinal study of young people in England: the activities and experiences of 17 year olds: England 2008. London: DCSF
8. Office for National Statistics (1997): Psychiatric morbidity among young offenders in England and Wales. London: Office for National Statistics.

Long Term Medical Conditions

Description of clinical concerns or groups of conditions covered

The World Health Organisation (WHO) defines long term conditions (LTCs) as health problems that require ongoing management over a period of years or decades. LTCs are conditions that cannot currently be cured but can be controlled with the use of medication and/or other therapies (WHO 2002). These conditions result from disease, damage, disorder to the body which then impacts on the individual and their family. Examples include predominantly single organ problems such as diabetes, epilepsy and asthma, and multi-system disorders such as cystic fibrosis or autoimmune disease. Neurodevelopmental and neurodisability conditions such as ASD, ADHD and motor disorders are covered in a separate chapter in this prospectus (pages 20-23). The focus of this chapter is LTCs not directly related to neurological or mental health conditions.

Incidence/prevalence:

The incidence/prevalence of the more important LTCs in children are as follows:

- Around 1.1 million children and young people (1 in 11) in the UK have asthma, making it the most common long-term medical condition.
- Around 1 in 500 children in the UK develop some form of cancer by the age of 14, making it the most common cause of death from disease for children and young people.
- Around 29,000 children and young people in the UK have diabetes, with about 26,500 of them having Type 1 diabetes, 500 having Type 2 diabetes, and a further 2,000 with diabetes whose diagnosis is unknown.
- Some 600,000 people in the UK have epilepsy - around 1% of the population - with young people under 18 accounting for around 10% of this total.

Service components delivered by community child health services

Most children with long term conditions are under shared care between their General Practitioner and their local hospital based paediatric services, with some needing to access additional specialist services. Depending on local service configuration and pathways, the contribution by community child health services is variable. It is important that CCHS work collaboratively with local hospital based paediatric services and tertiary services for this client group, facilitating a smooth patient journey and contributes appropriately, but not duplicating services provided elsewhere. Regardless of the underlying medical condition many of these children have difficulties with feeding, toileting, sleeping, behaviour social integration and educational achievement. Managing these issues requires a local multiagency team to complement the specialist elements of care provided often in hospital settings.

Examples of contribution by community child health services include:

a) Prevention and early recognition:

- National childhood immunisation programme;
- Local health education and other preventative initiatives;
- Local data management and service coordination for the national neonatal screening programme;
- Healthy Child Programme;
- National Child Measurement Programme.

b) Assessment :

- Assessment and diagnosis of LTCs in conjunction with primary, secondary and tertiary services;
- Specialist clinics: epilepsy, enuresis, encopresis, tube feeding;
- Advice to schools and local authority for children with LTCs;
- Integration with health and social care to develop a single care plan.

c) Management:

- Management of children with LTCs in conjunction with primary, secondary and tertiary services, including contribution to share care pathways;
- Specialist clinics: epilepsy, enuresis, encopresis, tube feeding;
- Care plan for school based management for children with LTCs including management of attendance during exacerbations/hospital admission;
- Facilitate training of school staff in supporting children with LTCs;
- Specific therapies including rehabilitation after an acute event;
- Co-ordination of the multidisciplinary and multiagency team;
- Specific treatment and procedures as provided by Community Children's Nursing Team.

d) Co-ordination of care and support:

- Servicing and chairing Multidisciplinary meetings e.g. early participation in education and social service reviews.

Potential improvements/developments

- Closer working with primary care and general paediatric providers at all levels, reviewing and establishing joint pathways for specific LTCs as appropriate
- Strengthening the capacity for community child health services to contribute at every stage of the patient journey, particularly for those with neurodisabilities and LTCs. Strengthening community paediatric nursing services should be considered strongly.
- Embedding community paediatric expertise in the development of community based specialist services ('Polyclinics' or 'Polysystem' equivalent)
- National survey of involvement and formal recognition of Community Paediatricians in LTCs, and working towards agreeable tariffs in this area.

References

1. Royal College of Paediatrics and Child Health, Modelling the Future: A Consultation Paper on the Future of Children's Health Services (September 2007) p. 59
2. Health for North East London. Meeting the children of North East London's health needs: case for change and model of care (2009)
3. Paul Treadgold. Long-term Conditions AYPH Research Summary - February 2012
4. NICE (2010). Nocturnal enuresis, the management of bedwetting in CYP

Palliative care services

Description of clinical concerns or groups of conditions covered

“Palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care following death and bereavement” (ACT 1997). “The goal of palliative care is the achievement of best quality of life for patients and their families, consistent with their values, regardless of the location of the patient” (WHO 1998).

At one level, it is the care that most clinical practitioners would strive to achieve for all the children and families they are involved with, regardless of their diagnosis, threat to life or other circumstances.

One definition of a life-threatening condition [in childhood] is any illness or condition developed in childhood (before the age of 19 years) whereby the child is likely (a probability of greater than 50%) to die prematurely (before the age of 40 years), or any condition developed in childhood that without major intervention (which itself carries a significant mortality) will result in the child dying prematurely. Short term/acute illness/injury and mental health diagnoses are excluded.

Children requiring palliative care fall into two groups, those with malignant conditions and those with non-malignant conditions. The majority of malignant conditions are now curable, so only a minority have a terminal phase requiring palliative care, whereas the majority of non-malignant conditions are not curable. Non-malignant conditions fall into two further groups - neurological conditions where there is a profound impact on everyday living through severe learning difficulty or impaired sensory/motor skills, and non-neurological conditions often needing intensive therapy regimes to maintain life e.g. cystic fibrosis, renal dialysis, or cardiac disorders. Both groups of conditions impact on quality of life for the child and their family in different ways.

Incidence/prevalence:

- The annual number of children likely to require access to palliative care services in the UK, excluding neonates, is estimated to be 23,500 (ie 16 per 10,000 population aged 0-19).
- The number of neonates requiring access to palliative care services is estimated to be 1,473 (ie 1 per 10,000 population).

Service components delivered by community child health services

A multidisciplinary model is essential. Children's palliative care services require a leading paediatrician supported by a team consisting of community children's nurses, clinical psychologists, social workers, therapists and healthcare assistants. The exact configurations and skill mix of the team depends upon existing services, but the aim is to create an integrated service that forms a team around the family.

The input from CCHS varies greatly across the UK. In some areas there are dedicated palliative care nursing teams for children with life limiting conditions, and in others support is provided by generic children's community nursing services. Community Paediatricians provide medical expertise and leadership in some areas. Access to specialist palliative services for advice and management is available in some major centres and from staff in some children's hospices but this is not consistent across the UK.

Service objectives

- Provide family-centred care in both community and hospital settings for children with life-limiting/life threatening illness
- Offer support and advice for the child, family and staff
- Provide education for the child, parents/carers, family, schools and professionals in the community, hospital and voluntary sectors
- Co-ordinate care between home, clinic, hospital and respite/residential services, liaising with fellow professionals as appropriate
- Provide specific advice on and treatment of pain and symptoms
- Assist with care of the child at home or in hospital in the terminal stages of their illness in collaboration with the family, the multidisciplinary team and Primary Care
- Provide bereavement support for family members and fellow professionals
- Provide an evidence-based resource centre for paediatric palliative care

Potential improvements/developments

- Review of national picture of palliative care provision
- Improved awareness of the need of palliative care amongst CCHS and defining the role of Community Paediatricians

References

1. Palliative Care Statistics for Children and Young Adults. Department of Health, 2007
2. NHS Scotland. Paediatric Palliative Care Guidelines
http://www.palliativecareguidelines.scot.nhs.uk/paediatric_palliative_care/
3. Together for Shorter Lives <http://www.togetherforshorterlives.org.uk/>
4. Oxford textbook of palliative care for children edited Goldman, Hain, Liben.
5. Integrated Multi-agency Care Pathways for Children with Life-threatening and Life limiting Conditions. ACT 2004

Audiology

Description of clinical concerns or groups of conditions covered

Paediatric Audiology Services provide assessment and management of children who are suspected of having a hearing impairment, or where a hearing impairment needs to be excluded e.g. as part of a more general developmental assessment for children with communication difficulties, or assessment for special educational needs. Paediatric Audiological Medicine encompasses a number of associated elements, including:

- Congenital permanent hearing impairment, either in isolation or as part of a more complex neurological condition
- Progressive and acquired hearing impairment
- Aetiological investigation of hearing impairment and genetics
- Auditory neuropathy spectrum disorders
- Auditory processing disorders
- Glue ear
- Balance disorders
- Tinnitus and hyperacusis
- Non-organic hearing loss
- Mental health problems in deaf children
- Educational advice

Incidence/prevalence

1-2 per 1000 children are born with significant permanent hearing impairment, and a similar number develop a hearing loss during childhood. In the pre-school years many children (at least 50%) have a temporary conductive hearing impairment.

Hearing impairment is not a discrete condition, and has an underlying medical cause. Depending on its type, degree or cause hearing impairment can have far-reaching consequences, e.g. language and behavioural development, social, mental health and educational effects. About 40% of children with permanent hearing impairment have additional medical and/or developmental problems. Assessing a child with suspected hearing impairment can be very difficult and fraught with pitfalls, particularly when there are other problems, e.g. children with autism, ADHD, developmental delay, social problems.

Service components delivered by community child health services

Paediatric Audiology Services are multidisciplinary with a number of overlapping disciplines, which include:

a) Prevention and early recognition:

- Preventative initiatives e.g. immunisation programmes, genetic counselling
- Newborn Hearing Screening Programmes

b) Assessment:

- Paediatric Audiology Services, which are normally staffed by experienced Paediatric Audiologists, with medical support provided by an appropriately trained and competent doctor, preferably at consultant level, to be responsible for providing medical input at every stage of the care pathway
- Other medical specialties such as Community Paediatrics, ENT, Genetics, Speech and Language Therapy

c) Management:

- Provision of hearing aids and on-going monitoring and support
- Referral to local child development and education services including speech and language therapy, the Hearing Impairment Team and Teachers of the Deaf
- Referral to other medical services for intervention e.g. ENT, Cochlear Implant Team

c) Coordination of care support:

- Close liaison between health and education services for deaf children;
- Networking between secondary and tertiary care, facilitating access to specialists assessment and intervention when appropriate, and providing shared care locally;
- Liaison with local and national voluntary organisations e.g. National Deaf Children's Society.

Potential improvements/developments

- Despite investment and improvement, Paediatric Audiology Services continue to vary in a number of ways, chiefly staffing resources and quality. Initiatives to address this variability and formulation of national level standards will be helpful.
- There is an increasing tendency for vacant medical posts in Paediatric Audiological Medicine being replaced by Audiologists. This will have implications on future service models, pathway and quality. Service providers will need to be mindful of this.

References

1. Transforming Services for Children with Hearing Difficulty and their Families; A good practice guide (DoH 2008)
2. Quality Standards in the NHS Newborn Hearing Screening Programme (DoH, July 2010)
3. Quality Standards in Paediatric Audiology: Guidelines for the early identification and audiological management of children with hearing loss (NDCS 2000)
4. British Association of Audiovestibular Physicians: Clinical Standards (BAAP 2011)

Opportunities for Teaching and Training

Relevance of Community Child Health in the training curriculum

Community Child Health departments are responsible for delivering specialist paediatric teaching and training to health professionals and allied agencies (including education and social care) covering a wide range of disciplines including child public health, looked after children, safeguarding, neurodisability and neurodevelopmental conditions. Community paediatricians are involved in many aspects of a child's life, and can have an input at any point in their and their family's life from the time a child is born to when they leave fulltime education.

Community paediatricians contribute at a number of levels in service delivery from local service provision, regional teaching and training of other health professionals and strategic implementation of national programmes such as 'The Healthy Child Programme'.

Community paediatricians are an integral part of multi-agency and multi-disciplinary working, encouraging full activity and participation of all children. Within CCHS, health promotion, prevention and treatment are combined in all aspects of care, whatever the complexity of the child's condition.

Current interest in paediatrics and community child health amongst trainees

Approximately 7-8% of UK medical students decide on paediatrics, a small but growing proportion of these choose Community Child Health as their final career. Current figures show that there are about 60 higher specialty trainees in Community Child Health in the UK. They contribute to on call paediatric rotas during their training. Almost all Community Child Health Services contribute to Level 1 and Level 2 training (all paediatricians must do 6 months CCH as part of Level 2 training). Pressure on training places in some Deaneries is expected as interest in the specialty expands.

Potential training that can be delivered by Community child health services

A wide range of teaching and training opportunities are delivered by community child health services. Teaching themes can be adapted to suit the audience be they medical, social care, education or other agencies.

Child Public Health

At a strategic level, Community Paediatricians work with public health to implement the Healthy Child Programme. Training is provided to health visitor, school nurses and allied professionals, so that they can carry out the healthy child programme as set out by the Department of Health.

Training is provided to school nurses in immunisations and vaccinations so that they are able to carry out vaccination programmes effectively. Community paediatricians also run local vaccination helplines accessed by GPs and nurses providing continuing professional development and support to health professionals. Community Paediatrician contributes to local vaccination steering groups to allow safe and effective delivery of vaccines,

maintaining good clinical governance and providing training in the medical aspects of vaccinations.

Community paediatricians run child health promotion courses and updates for GPs allowing them to manage children in primary care more effectively. They also provide specialist input on a number health initiatives and steering groups run by the local PCTs including high profile areas such as obesity, accident prevention & breastfeeding.

Neurodisability and Neurodevelopmental conditions

Given the unique role of working across agencies Community Paediatricians have an important function in teaching and training professionals, not just in health but also in education and social care to ensure a good understanding of each other's responsibilities and to allow efficient working between agencies. Community paediatricians support and facilitate training for school staff to manage children with all kinds of disability and/or learning disability and also with medicines management.

Community paediatricians take a lead role in diagnosis and management of Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD). Community paediatricians provide training and updates to health visitors, community and school nurses, GPs and educational services so that they are up-to-date in their knowledge of these conditions so that they can provide effective services to the child and their families.

Safeguarding

There has never been a greater need for training in child protection. With Lord Laming's report *The Protection of Children in England* (2009) came a heightened awareness of the importance of ensuring that staff in all areas of children's services knows how to recognise abuse and what to do when it happens. There are different levels of training needed depending on the level of responsibility, and Community Paediatricians provide this training at all levels. Professor Eileen Munro's review of Child Protection (2011) specifically made references to improve learning, and in particular from practice and findings of Serious Case Reviews.

Local Safeguarding Children Boards (LSCB) are a statutory requirement and it is mandatory for a paediatrician (almost always a Community Paediatrician) with in depth knowledge of safeguarding and the ability to work with allied agencies to sit on the Board. In this Community Paediatricians bring their expertise to the LSCB through their participation and contribution to the strategic working of the LSCB and participate in the LSCB training events.

Looked After Children (LAC)

Community paediatricians provide the sole medical input on statutory fostering and adoption panels, and train members of these panels with regard to health issues surrounding LAC and possible adoptions. The training aims to improve the matching process and make it more efficient therefore avoiding health related delays.

Training is provided to LAC nurses and GPs so that they may carry out assessments on children who have previously been seen by a Community Paediatrician.

Outcome measurement for success of training programmes

- GMC trainee and trainer questionnaires
- Formal and informal feedback from students and trainees.
- Number of Higher Specialist Trainees who successfully complete their CCT in Community Child Health.
- Access to GP initial training and updates in Child Health Surveillance for all those who require it (e.g. most registrars will wish to do the initial training, updates might be provided every other year)
- Compliance with School nurses training requirements in vaccination/immunisation updates
- Feedback from health professionals having safeguarding training
- All paediatricians and other specialists who work with children should have up to date Level 3 training (CQC requirement)

Potential improvements/Developments

- An active teaching and training department would encourage research allowing areas of excellence and expertise to develop in the department.
- Enhanced comprehensive joined up working facilitates improved activity and participation of vulnerable children and their families.

References

1. M Blair, S Koury, T De Witt, D Cundall. Teaching and training in community child health: learning from global experience. Arch Dis Child Educ Pract Ed 2009;94:123-128
2. RCPCH. Modelling the Future. A Consultation paper on the future of children's health services. September 2007
3. DfE (2011), The Munro Review of Child Protection: Final Report. A child centred system.

Future research, service evaluation and improvement

In his document High Quality Care for All, Lord Darzi set out the commitment that quality would be the organising principle of the NHS. Clinical audit, service evaluation and continual improvement of services using evidence based principles are essential within Community child health services.

Like all medicine it is essential for Community Child Health to have clinical care based on robust evidence. Community Child Health has a strong history of research into the social determinants of health and health inequality, childhood disability and safeguarding. There is now an increasing need for intervention research where we test the effectiveness of community based interventions at scale, using the skills of clinicians, clinical academics and pure scientists within research networks. In this prospectus we have outlined some potential areas for development in Community Child Health at the end of each chapter.

Small scale research projects are possible at a local level, but Community Paediatricians are increasingly working with research colleagues in multicentre studies through research networks. Community Paediatricians are in a unique position to analyse the needs of their local community, work within multidisciplinary teams to create research questions and research networks answer these questions using the resources of funding agencies such as the National Institute of Health Research (NIHR). They can also recruit subjects into multi-centre trials.

Community Child Health as a speciality has strong links with research institutions, public health and policy makers. It is thus in a unique position to improve the health of the nation's children

Key References

- Health and Social Care Act 2012
- BACCH (2011) Improving the practice of commissioning services for children and families: Guidance to providers in responding to commissioners.
- DH (2010) The Operating Framework for the NHS in England 2011/12
- DH (2009) Healthy Lives, Brighter Futures
- DH (2008) Better Care: Better Lives
- Social Exclusion Task Force (2007) Reaching Out: Think Families (Cabinet Office)
- DCSF (2007) Children's Plan: Building brighter futures
- RCPCH (2007/8/9) Modelling the Future 1, 2 and 3.
- DH (2007) Children's health, our future: A review of progress against the NSF for Children and Young People and Maternity Services -2004
- DH (2006) Our Health, Our Care, Our Say: a new direction for community services
- DH (2004) National Service Framework for Children, Young People and Maternity Services
- DfES (2003) Every Child Matters
- DH (2009) Healthy Child Programme: pregnancy and the first five years of life
- DH (2009) Healthy Child Programme: from 5-19 Years
- 'Fair Society, Healthy Lives', The Marmot Review 2010
- Intercollegiate Committee (2007), Services for children in emergency departments, RCPCH
- DH (2007) Mental Health Act
- DH (2007) Children's health, our future: A review of progress against the NSF for Children and Young People and Maternity Services -2004
- DH (2004) National Service Framework for Children, Young People and Maternity Services
- HM Government (2004) The Children Act 2004
- HM Government (2010) Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children
- DH (2006) standards for Better health Core Standard 2 (safeguarding) Standards 11 and 12
- HM Government (1989) The Children Act 1989
- HM Government (2004) The Children Act 2004
- Laming report (2009)
- NICE Guidance (2010) Promoting the quality of life of looked- after children and young people (2010)
- DCSF (2009) Statutory Guidance on Promoting the Health and Wellbeing of Looked After Children, Office for National Statistics, DFE Children in Need in England Census 2009-10,
- SEN and Disability Green Paper 2011
- DH: People with Learning Disabilities in England 2010: Services & Supports

- Report of CYP Outcomes Forum, 2012
- BACCH: Community Paediatric workforce requirements: to meet the needs of children in the 21st century
- RCPCH (2008): Model job description for Designated Doctor for Child Protection
- RCPCH (2008): Model job description for Named Doctor for Child Protection
- BAFF (2008): Model job descriptions and competences for medical advisors in adoption and fostering
- RCPCH (2005): Guidance on completing a job description for Consultant Paediatricians in CCH
- RCPCH (2005): Guidance on completing a job description for Associate Specialist Paediatrician in CCH
- DH (2011): Getting it right for CYP, overcoming barriers in the NHS so as to meet their needs ('Kennedy Report')
- DfE Green Papers (2011 & 2012). Support and aspiration: A new approach to special educational needs and disability. Consultation, progress and next steps.
- Education Act (1996)
- SEN and Disability Bill (2001)

Scotland

- Children (Scotland) Act 1995
- Protecting Children: A Shared Responsibility. Guidance for Health Professionals in Scotland (the Pink Book). 2000.
- Criminal Justice (Scotland) Act 2003
- The Protection of Children (Scotland) Act, 2003
- <http://www.mars.stir.ac.uk/resources/wp-content/uploads/2011/04/123.-The-Protection-of-Children-Scotland-Act-2003.pdf>
- A guide to Getting it Right for Every Child, 2008
- <http://www.scotland.gov.uk/Resource/Doc/1141/0065063.pdf>
- The National Guidance for Child Protection in Scotland, 2010
- <http://www.scotland.gov.uk/Resource/Doc/334290/0109279.pdf>
- Protecting Children and Young People - Interim guidance for Child Protection Committee for Conducting a Serious Case Review, Scottish Executive, 2007
- See <http://scotland.gov.uk/Resource/Doc/174043/0048532.pdf>
- Sexual offences (Scotland) Act 2009
- Looked after children & young people: we can and must do better, 2007
<http://scotland.gov.uk/Resource/Doc/162790/0044282.pdf>
- The Education (Additional Support for Learning) (Scotland) Act 2004

Wales

- The Children Act 2004 (Commencement No 8) (Wales) Order 2008
- Government of Wales Act 1998
- Government of Wales Act 2006
- National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008
- Welsh Assembly Government (2006): Safeguarding children: working together under the Children Act 2004
- All Wales child protection procedures review group (2008). All Wales child protection procedures
- Welsh Assembly Government (2004): Children and young people: rights to action

Northern Ireland

- Children (Northern Ireland) Order 1995
- The Criminal Justice (Northern Ireland) Order 2008
- The Protection of Children and Vulnerable Adults (Northern Ireland) Order 2003
- The Safeguarding Vulnerable Groups (Northern Ireland) Order 2007
- The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)

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