

YOUNG AT HEART

**GETTING SERVICES RIGHT FOR
CHILDREN AND ADOLESCENTS**



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There is still much to do

The NHS is not very good at focusing on children and young people. The question is why? It is too complex? Are we complacent even though we know that the origins of so much adult disease, whether physical or emotional, starts in childhood? Or are there persisting inequalities? While we have stopped seeing children as small adults, we have yet to properly recognise the needs of adolescents and people in early adulthood. There is a lot to do to improve outcomes.

The children's national service framework was a great start, built on by a new Child Health Strategy. We are not short of good policy; we are short on implementation. This means we need to focus on enablers and barriers, issues such as the use of information, workforce, joint working with local authorities, using the views of children and young people and their families to shape services. In short, we need to get smarter and learn from each other.

In some parts of the country there are fantastic examples of good practice where children and their families are at the heart of services. The benefits are clear to see. This supplement highlights the challenges in developing children's services and how innovative solutions are leading to better outcomes for children, young people and their families. While this can be complex, it is achievable.

This is not a comprehensive guide to what and how a should commission or provide in children's health services. There are important areas, such as safeguarding, that we have not been able to cover here. But in identifying some of the challenges your colleagues have faced and sharing examples of good practice, we hope to inspire you to commission and deliver services locally that really make a difference to children's health and wellbeing in your area.

It is an exciting time to be working in children's health. We know much more now about what works to improve their physical and emotional wellbeing, and how this resonates throughout adult life. Prevention and early intervention are essential along with good partnership working at a local level. We must not forget those most vulnerable to poor health outcomes, such as socially excluded groups.

It is vitally important to get services right for this population group. With this in mind, the Healthy Child Programme can deliver a universal preventative service at the same time as focusing on vulnerable babies, children and families. Recognising the benefits of the programme for zero to five-year-olds, we have extended it to the age of 19 to encompass transition through adolescence and on to adulthood.

We are still hospitalising too many children and there are issues to address in primary care, accident and emergency and inpatient services. The profile of long term conditions is different in children from adults but no less important.

Clarity about care pathways between primary, community, secondary and tertiary care is essential. Developing networks is a crucial component to delivering as much care as possible closer to home at the same time as centralising care for rarer illnesses to achieve the best outcomes. There are many examples here, the newborn, children's surgery, diabetes and rarer conditions such as cancer. Improving networks for safeguarding children must also become part of modern thinking.

We know finances are getting tighter, and we will all be under greater pressure to show we are running services in the most efficient way possible. Quality and productivity therefore need to be top priorities when planning, commissioning or providing services, as well as strengthening joint working arrangements. Integration across the NHS to make us better partners to work with local authority colleagues undoubtedly helps.

We know it won't be necessarily straightforward or easy, but with strong consistent leadership from NHS managers and engagement of clinicians it can be achieved.

After all, children are our future. ●



START AS YOU MEAN TO GO ON

The Healthy Child Programme helps parents to lay the foundations of health and wellbeing at a child's birth

Pregnancy and the first years of life are some of the most important stages in a child's development. This is when the foundations of future health and wellbeing are established and is a time when parents are particularly receptive to learning about how to care for their child and making necessary changes.

The Healthy Child Programme, formerly the Child Health Promotion Programme, promotes universal public health for all children and families. It consists of a schedule of reviews, immunisations, health promotion, parenting support and screening tests that promote and protect the health and wellbeing of children from pregnancy through to adulthood. Providing a high quality programme that is visible and accessible to families with children is a core health responsibility contributing to the

COMMISSIONING THE TWO-YEAR REVIEW

Commissioners are responsible for deciding what outcomes they wish to see for young children and families, what funding is available and who will provide the Healthy Child Programme. The following selection of commissioning requirements for the programme and the two-year review reflect national competencies for commissioning:

- The review is to be commissioned in collaboration with local providers as part of the overall programme
- The HCP must be jointly commissioned by The Children's Trust and highlighted within local area agreements with active NHS and practice-based commissioning involvement
- To have in place methods for gathering user feedback on the programme, especially from disadvantaged groups, and changing local contracts accordingly
- For the commissioning to be clinically led by public health with the involvement of frontline staff
- Currency and pricing options that are realistic in what can be achieved within the funding provided
- To base local contracts on national service specification for the programme



A guiding hand: parents need the most support during their child's early years

goals of Every Child Matters and services provided in Sure Start children's centres.

The Healthy Child Programme, led by health visitors, is increasingly being delivered through integrated services that bring together Sure Start children's centre staff, GPs, midwives, community nurses and others. Children's centres are a way of delivering community-based services, and are visible and accessible to families who might be less inclined to access more traditional services.

It is important for primary care trusts to deliver the programme by jointly planning and commissioning services with local authorities, making use of arrangements that children's trusts already have in place. Monitoring, evaluating and improving its quality should be a primary aim for PCTs.

The programme reflects new evidence about neurological and developing biological systems that can affect behaviour and physiology later on in life. A child's brain develops rapidly during pregnancy and the first two years of life and is influenced by the emotional and physical environment as well as by genetic factors. The effects of maternal anxiety and depression in pregnancy are now known to be mediated by chemical changes in the infant brain. Early interactions directly affect the way the brain is wired, and early relationships set the "thermostat" for later control of the stress response.

This all underlines the significance of pregnancy and the first years of life, and the need for mothers and fathers to have support available to them during this time.

KEY MESSAGES FOR THE TWO-YEAR REVIEW

- Prioritise the promotion of emotional and communication skills, support for positive relationships in families and obesity prevention
- Work effectively with mothers and fathers to develop self efficacy and support change
- Universal coverage achieved through integrated working across all children's services, including Sure Start Children's Centres and general practice and outreach for disadvantaged groups
- Reduce unequal outcomes for children
- Promote the health of two-year-olds through community and public health actions
- Use new media tools for effective delivery and productivity
- Set up the right infrastructure to support delivery at two years
- Deliver the review in innovative and efficient ways that result in improved outcomes for all children and their families

For the NHS to actively contribute to reducing inequalities in children's health, wellbeing and achievement, it must focus on the most vulnerable children and families, and allocate resources accordingly.

One of the Healthy Child Programme's pivotal roles is to identify children in high risk groups who have low protection, and to ensure that these families receive personalised services. Poverty is one of the biggest aggravating factors linked to poor health outcomes. Poorer children are less likely to be breast fed, more likely to be exposed to tobacco smoke and more likely to be injured at home and on the roads.

Progress during this time of rapid development is reviewed at set points: birth; 10-14 days; during the first and second year of life; as well as continuously by the health visiting teams as judged necessary. Detailed information is already available at these stages and the Department of Health has produced a guide for NHS professionals to compile information on the specific content and process of the two-year review.

Professor Mitch Blair, a consultant paediatrician and adviser to the Department of Health on the Healthy Child Programme, wrote the review to update practitioners, recommend tools to support the review and suggest ways of delivering a progressive universal review that maximises quality, productivity and cost effectiveness.

He says that the era of evidence based medicine has made it imperative to think even more closely about the programme.

"The guidance for the two-year review set out to gather the best and latest evidence about what should be being done across the four areas of screening, immunisation, parenting support and health promotion," he explains. "This is not a one size fits all model, but what we are saying is that commissioners and service providers need to get practical tools to parents and think innovatively, they need to disinvest in things that are not working and use data tools, evidence, media and technology, as well as looking at the skill mix of their teams."



THE HEALTHY CHILD PROGRAMME ONLINE TOOL

The Healthy Child e-learning for health online tool is being designed for healthcare professionals who are promoting the health and wellbeing of infants and children. The government has worked on developing the tool with a consortium led by the Royal College of Paediatrics and Child Health. The tool is also intended to support the implementation of best practice set out by the Department of Health's Healthy Child Programme.

The learning materials cover a range of public health priorities for infants and children:

- Family health
- Safeguarding
- Positive parenting and parenting issues
- Development and behaviour
- Growth and nutrition
- Immunisation
- Health promotion
- Screening

The adolescence tool is already available online and free for all NHS staff. The government intends to roll out the zero to five paediatrics by December 2010. The final section


for five to 11-year-olds will complete the e-learning tool for children from zero to 19.

Karen Turner, the Department of Health's deputy director of delivery programmes for children, families and maternity, says: "It is about helping those professionals with their knowledge in terms of prevention and early diagnosis."

The tool has 20 online lessons that health professionals can work through and use to self-assess. "It is designed so it can be done by individuals or as part of a multi-disciplinary team," she says.

There are thousands of health professionals who are already using the adolescent tool and Ms Turner is hopeful that this number will increase in the future.

"Improving child health does not have to be expensive," continues Ms Turner. "It is about using opportunities to best effect, not about a huge amount of new staff. It is about thoughtful practice and this is where the e-learning tool helps; it provides frontline training that is accessible for working with children and young people."



Invest in the future:
guidance early on in
parenthood pays
dividends later

Nurses with a family focus

The Family Nurse Partnership offers specialist help to young people finding early parenthood challenging

The Family Nurse Partnership is a specialist preventative programme for some of the most vulnerable children and families. It is an intensive, nurse-led home visiting programme for first time, young parents.

Family nurses visit vulnerable young mothers from early pregnancy until the child is two years old, building a close, supportive relationship with the whole family and guiding mothers to make healthy decisions for themselves and their child, form positive relationships with their babies and become economically self-sufficient.

The programme is voluntary and has been taken up by 90 per cent of the families who have been offered it.

The government made a commitment to trial the partnership model as part of the Social Exclusion Action Plan in September 2006 and it was piloted in 10 locations. After a promising early evaluation, the number of areas testing the programme has been increased so that there are now 50 sites.

Each team in the partnership is made up of a supervisor and between four and six family nurses, each with a case load of approximately 25 families. Family nurses receive additional training to deliver the programme with most coming from a background in health visiting, midwifery or mental health. These teams work closely with maternity and child health services and link families to Sure Start Children's Centres so they can benefit from their activities.

The programme was developed over 30 years ago in the US by Professor David Olds at the University of Colorado and licensed to the NHS. It focuses on improving outcomes across three areas:

- antenatal health
- child development and school readiness
- economic self-sufficiency.

In the US, large scale clinical trials have shown that the programme brings significant and consistent benefits to the health and wellbeing of the most disadvantaged children and their families in both the short and long term.

The outcomes include better antenatal health; fewer subsequent pregnancies; better prenatal health; reductions of between 50 and 70 per cent in child injuries, neglect and abuse; improved school readiness and increases in the father's involvement.

Kate Billingham, project director for the partnership at the DH and Department for Children, Schools and Families, says the early years of a child's life establish the foundations for their health and wellbeing in adult life.

"The new science around neurological development has created an imperative to work intensively with the most vulnerable families from pregnancy to the first few years of life," she says.

She says there is a need for specialist

intensive preventative programmes for some families as well as universal preventative services for all families.

Evidence from the US shows that the partnership will also bring value for money savings. For every dollar invested, there is a five-dollar saving. By the time the child is 15, there are savings of over \$15,000.

In England, the average cost of the partnership is around £4,500 per family over two and a half years, which is low when compared with the cost of a hospital admission, of a child in care or receiving mental health services. It is still being tested across the UK with 50 sites and 3,500 families are benefiting from the programme.

Ms Billingham says that more evidence of the outcomes and how it is working in England is needed before it can be rolled

'The programme has been taken up by 90 per cent of the families offered it'

out, but the early evaluation by Birkbeck College and the experience of families and the family nurses is promising.

NHS Berkshire East family nurse Nikki Jefferies says the partnership is an evidence-based programme that focuses on inequality.

"There is evidence to show that it provides value for money in the US and here at Berkshire East we are involved in piloting the first wave of the programme in Slough to show how it can work here," she explains. "I have seen first hand that it has real power to make a difference to families. It is the relationship between the nurse and the client along with the methods and material that are key to enabling the client to change their behaviour."

The partnership works across five main areas: personal health, the life course, the maternal role, environmental health issues; and family and relationship issues.

"The goal is to help young parents set plans about returning to work and education and what it means to become a mum and the relationship they will have with their children," says Ms Jefferies. "It can mean real savings in the long term in terms of emotional and physical health for children and their parents."

The Family Nurse Partnership is working with high risk families and young parents who bring psychological difficulties and chaotic life experiences into parenthood. It explores difficult issues with challenging clients and they receive weekly one to one supervision with the nurses. The complexity of the work means it needs highly skilled professionals and the research so far has shown the best outcomes are achieved when it is delivered by nurses. ●

Professor Blair highlights Taunton, South East Essex and Derby as examples of places where the Healthy Children Programme 0-5 is already working very well.

"There is good and bad practice, where it works well there is good leadership, health visitors are willing to work across local authority boundaries with the NHS, the voluntary sector and education services all participating," he says. "Where it works badly there has been no training of staff for years, there is a lack of professional leadership, the service is over-managed in terms of ticking boxes but there is no innovation and there is a culture of fear and job losses."

He highlights research from the US which shows that every dollar spent at this stage in a child's development can save \$7 in the longer term.

"We need a big investment in early years and I don't think commissioners have this, because by their nature they have to look at the short term. We need a dialogue about the short, medium and long term investment for the future. There is a danger bits of the services are being commissioned and others are not," he adds. ●

YOUNG AT HEART

Planners must use resources effectively if they are to meet government health goals for five to 19-year-olds

Last October, the Department of Health and the Department for Children, Schools and Families launched the Healthy Child Programme for five to 19-year-olds, following a review of the evidence by Professor David Hall and colleagues. This followed the launch in February 2009 of the child health strategy *Healthy Lives, Brighter Futures* and built on the existing Healthy Child Programme for zero to five-year-olds and the national service framework.

The programme sets out the good practice framework for prevention and early intervention services for children and young people aged five to 19, and recommends how health, education and other partners working together across a range of settings can significantly enhance a child's or young person's life chances.

The foundations of the programme lie in the government's five outcomes identified by children and young people as fundamental to their lives, as set out in the government 2004 report *Every Child Matters*. These are to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic wellbeing

The programme is designed to help local children's services planners use their resources as effectively as possible, informed by the best available evidence. In particular, it aims to help them base their children's and young people's services on a robust needs assessment, prioritise programmes that are supported by appropriate evidence, stop using interventions that are shown to be ineffective, and to make the best use of their workforce.

Sheila Shribman, national clinical director for children, young people and maternity at the DH, says that in the current economic climate, with pressure on resources, the focus should be on what is proven to work.

"Reviewing existing working practices against the good practice framework set out in the Healthy Child Programme may, in some instances, lead to change, as we move towards [building] one team around the child. Similarly, doing what we ought to do – underpinned with good evidence and ongoing evaluation – rather than what we have always done, is likely to change working practices," says Dr Shribman.

"The programme emphasises that robust needs analysis is a prerequisite to effective and efficient resource allocation. This is an



THE HEALTHY CHILD PROGRAMME WILL BE MOST SUCCESSFUL IF:

- Staff are appropriately trained and skilled
- All services are delivered in the appropriate environment, for example, ensuring all health services for children are child friendly
- Service providers view young people holistically and not simply in terms of the presenting problems. This means they are alert to the interplay between multifactorial risks. For example, young people abusing drugs and alcohol will often have higher rates of sexual health and mental health problems
- All schools are Healthy Schools and are working towards health and wellbeing outcomes through the enhancement model
- All schools are working towards providing access to the full range of extended services
- Schools understand their responsibilities for intervening early to support at-risk children and young people
- All colleges and organisations are fully using the healthy further education framework
- The curricula for physical, personal, social, health and economic education are delivered effectively
- The core skills and competencies required by the five to 19 HCP Team are met
- The configuration of services and allocation of staffing and resources are underpinned by a systematic assessment of population needs
- Children, young people and their families/carers are consulted and engaged in service design and delivery

incremental early intervention programme that will build on existing good practice: everything that is described in the programme in terms of service provision, workforce development and delivery is already in operation or under development somewhere."

Dr Shribman says that new ways of working with teams spread across a locality and the further development of school nursing teams will offer opportunities to "capitalise on the skills and commitment of all who contribute to children's and young people's health and wellbeing".

The government's aim is that areas will start to use the programme as a schedule of good practice to evaluate and develop their local services. Dr Shribman adds that certain aspects of the whole programme from ages zero to 19, such as data capture



Patient approach:
resources are best
focused on already
proven practices

and analysis and information sharing systems, will be crucial to its success.

"In terms of the commissioning contribution to this agenda, commissions should be heavily involved in Children's Trusts, people should be able to commission in confidence knowing there is an updated review of the evidence for five to 19-year-olds and there is a greater clarity about it. It is up to commissioners to look at their local demographics and population and decide what they commission locally," she says.

Evidence shows that lifestyles and habits established during childhood, adolescence and young adulthood influence a person's health throughout their life. Up to 79 per cent of obese adolescents remain obese in adulthood, and adolescents who binge drink are 50 per cent more likely to be dependent on alcohol or misusing other substances

when they reach the age of 30. Failure to meet the health needs of children and young people stores up problems for the future.

The case for prevention and early intervention is reinforced by the long term costs of inaction and delay. Weight related problems for example are forecast to cost £50bn to the wider economy by 2050.

The 2002 Wanless report demonstrated the importance of public engagement with health and an evidence-based approach; using prevention and early intervention should reduce costs to society and to health, education and wider children's services in the long term.

The programme suggests commissioners consider withdrawing or avoiding activities that are not supported by evidence, such as routinely giving children a physical examination at school entry.

CHIMAT

The specialist Child and Maternal Health Observatory is a national public health observatory established to provide wide ranging, authoritative data, evidence and best practice relating to children's, young people's and maternal health. It is part of the Yorkshire and Humber Public Health Observatory, a member of the Association of Public Health Observatories.

ChiMat was established as a pilot project in October 2007 as a collaboration between Yorkshire and Humber Public Health Observatory, the Care Services Improvement Partnership, Children, Young People and Families Programme, the NHS Information Centre and the Healthcare Commission. It is funded by the Department of Health. It was launched as the National Observatory for Child and Maternal Health in February 2009.

The Observatory works with a range of stakeholders, including children's and maternity leads, commissioners, service improvement leads and performance managers in health and local government roles, government regulatory bodies and government departments, clinicians and health professionals.

Helen Duncan, ChiMat's programme director, explains that the opportunity offered by ChiMat was highlighted in *Healthy Lives, Brighter Futures*.

"Services need effective data and information to improve and monitor outcomes and support inspection. We work behind the scenes providing basic information and analysis so it is done once centrally for everybody and not duplicated," she explains.

"We are putting together a one stop shop of knowledge, information and tools. ChiMat is free at the point of use, individuals can access information from the website and ask for additional information from us."

Dr Duncan says that ChiMat is also constructing regional networks, with staff working in each region with public health observatories, strategic health authorities and regional government offices.

One of the tools ChiMat provides to commissioners is a "data atlas" published using geographic mapping software that allows background demographic and service performance to be compared.

"It's easy for a primary care trust to see who they compare with statistically and where they are a statistically significant outlier. They can see at a glance where their performance is worse than the national average and we can show them where there are potential areas of concern and opportunities for improvement in comparison to other parts of the country. For example, where there are high rates of teenage pregnancy or obesity, we can give them the background information and then help them think about their priorities," explains Dr Duncan.



← The government hopes that by investing money now it will avoid greater costs to society in the long term. For example, evidence suggests that a sexual health service offering the full range of modern contraception to all young people could save at least £500m over 15 years. In 2005, the National Institute for Health and Clinical Excellence estimated that if 7 per cent of women switched from the pill to long-acting reversible contraception methods (doubling current usage to 15 per cent), the NHS could save around £100m each year through reducing unplanned pregnancies by 73,000.

It is more cost-effective to prevent ill health than to treat established disease, so a focus on prevention and early intervention has a vital role to play in breaking the cycle of health inequalities within families. Many problems take hold in early childhood and adolescence, making these crucial points at which to stage interventions.

Dick Churchill, associate clinical professor of primary care at the University of Nottingham, says there is an important link between schools and the NHS for children and young people.

"A lot goes on in schools that we in the NHS don't know about; it is important to share information across the boundaries at

'Evidence shows that lifestyles and habits established during childhood, adolescence and young adulthood influence a person's health throughout their life'

primary and secondary school entry between health and education, at the moment the two will have different health records," says Dr Churchill.

"Commissioners need to look at their needs assessment in particular and make sure that they are not over-providing services. They need to make sure that sharing information between services is a requirement of service providers and that there is cross-referral happening. There needs to be a continuity of services, [they] need to be more joined up, because at the moment there is a lot of duplication of service provision, information needs to be

made available and commissioners need to map what is already there," he adds.

Northampton General Hospital directorate manager for children's services Bob Butcher agrees: "I think that children's services have a propensity to be dwarfed by the adult agenda; targets and the drive to achieve them can leave children's services as an also ran. If we fragment children's services too much they can become a forgotten add-on," he warns.

"We need an integrated set of providers [of services to children], which then gives a much stronger focus and enables national guidelines to be met," he adds.

In order to achieve the Healthy Child Programme for five to 19-year-olds, ultimately what is needed is a skilled and flexible workforce, strong local leadership and an infrastructure that is capable of innovating, adapting and responding to the changing needs of children, young people and their families.

Strategic monitoring, evaluation and quality improvement by commissioners and service providers – and scrutiny by and involvement of children and young people and their families themselves – will be important factors in the programme's impact, effectiveness and success. ●

THE CONTRIBUTION OF THE SCHOOL NURSING SERVICE



Good point: school nurses are expected to lead health teams

The school nursing service lies at the heart of the school health team and forms part of the wider Healthy Child Programme team. The government document *Aiming High for Young People*, published by the Treasury and the Department for Children, Schools and Families in 2007, proposed reshaping the existing school nursing service to enable it to be at the centre of emerging or newly developed multidisciplinary teams being established as part of the Every Child Matters reforms.

The programme for five to 19-year-olds offers the opportunity to ensure – in line with

the Department of Health's commitment on access to school nursing – that schools have access to the expertise of school nurses and their colleagues. The breadth of provision will be determined by a local needs assessment.

There are good examples of services being reconfigured in this way, making better use of existing skills sets. The programme will offer opportunities to enrich the workforce, in terms of both skills and competencies, and leadership. There is likely to be a significant role for school nurses as leading, core members of the school health team.

The government hopes that school nurses will, over time, be increasingly leading and influencing, ensuring strong links and partnerships with other professionals and providers, according to local and school community needs assessment.

This is likely to involve co-ordinating the delivery of the programme in schools and across groups of schools, ensuring that health elements of the programme are delivered and quality and outcomes monitored, and providing services directly, especially where these require nursing skills and expertise.

THE BEST CHANCE OF SURVIVAL

Harnessing innovation to give newborn babies the best possible start in life not only works for their survival, it also helps ensure that their quality of life is the best that it can be



Demand for specialist neonatal care has increased by nine per cent in the past three years, but the level of neonatal care a baby may need will vary from minimal intervention for a few minutes or hours through to considerable support over many weeks, months or even years.

In 2007, the last year for which figures are available, 68,000 babies born in England were admitted to neonatal care and of these 19,500 were admitted to intensive care. At the same time as numbers of babies needing specialist care increased, there have been marked improvements in technology and treatment, so that there has also been an increase in the number of vulnerable babies who survive after being admitted for neonatal care.

Despite this, 2,127 babies died within their first 28 days of life in England in 2007, which is equivalent to 41 deaths per week, or six deaths per day. This is almost 50 per cent more than the number of children in the UK diagnosed with cancer in the same year and 50 per cent more than the number of people who died from MRSA. A staggering 60 per cent of all infant deaths occur during the neonatal period.

In 2007, the National Audit Office undertook a review of network arrangements for neonatal services in the NHS and raised concerns over the number of nurse vacancies, the variation in transfer arrangements around the country, and the lack of clear commissioning and financial arrangements in some units and networks.

To address these concerns, the government established The Neonatal Taskforce in 2008. This involved staff from across the NHS, including clinicians, managers, commissioners and educationalists as well as parent representatives.

A toolkit developed by the taskforce outlines the NHS view of high quality neonatal care and clarifies the responsibilities of those delivering and commissioning neonatal services. The toolkit is designed to stimulate the action needed to improve services.

These improvements will not all happen immediately. They will evolve over the next few years, as staff are recruited and trained. Commissioners and providers must decide how best to respond to this guidance with regard to their local service needs and resources, including the pace of implementation, which in some cases could take up to five years.

According to health minister Ann Keen: "Babies needing the support of neonatal services are our most vulnerable [patients] and we need to work together with their families to ensure that services are as good as they can be, and we have adequate resources and a competent, skilled workforce that is able to meet this worthy challenge."

Launching the toolkit, NHS medical director Professor Sir Bruce Keogh said: "Our goal must be to harness innovation, to optimise the health of newborn babies, so minimising the demand for neonatal care and to ensure that all neonatal services operate as efficiently and effectively as they can. In this way, we can ensure that NHS

staff, working with families and carers, can offer these children the best possible start in life.”

The toolkit identifies eight principles that cover the major areas of activity within the neonatal care pathway. These are:

- Organisation of neonatal services
- Staffing
- Care of the baby and the family experience
- Transfers
- Professional competence, education and training
- Surgical services
- Clinical governance
- Data requirements.

Neonatal services are based on strategic health authority populations and organised as 23 managed clinical networks across England, although several are managed together in consortia relating to specialist commissioning groups. Each network has, or is developing, its own care pathways, guidelines and clinical audit programmes. As it stands, specific arrangements have been identified and managed locally and, as a result, there is variation in network funding, in assumed roles and in stakeholder representation.

The toolkit advises that for neonatal care to be successful it needs to be based on a whole systems approach and commissioned on a network wide basis alongside both maternity and foeto-maternal medicine services.

Neonatal taskforce project manager at the Department of Health Allison Binns says that the starting point for commissioners and providers in terms of shaping good neonatal services is to ask themselves what they need to do locally and what they need to get right immediately.

“It is about changes in attitude and culture at an NHS staff level,” she says.

She admits that some of the elements of service redesign may take some years to change but insists that commissioners and providers must start now: “Look at what education, training and skill-mix you need in your area.”

The evidence suggests that a high quality of care for premature and sick newborn babies and their families is most likely to be achieved if all the elements of specialist neonatal care – including intensive, high dependency, special care, transfer services and neonatal surgical care – are commissioned together with all maternity and neonatal services across a managed clinical network. Neonatal care is also interdependent with obstetric and foeto-maternal medicine.

The toolkit suggests that this whole perinatal pathway of care should be commissioned, either by the relevant specialist commissioning group or collaboratively by primary care trusts.

Services that are an integral part of neonatal care include transfer services, maternity bed and neonatal cot location services, family-centred care, follow-up services, and allied health professional support during and following neonatal care.

The taskforce’s vision for neonatal services is that it should “deliver the best



‘There are some things they can put into action now without needing extra funding. For example, making sure that parents are involved in the care of their baby’

quality care in order to achieve the highest quality outcomes for premature and sick newborn babies and their families.”

It has found that the best way to achieve this is by:

- establishing a managed clinical network in which constituent neonatal and allied services work together
- ensuring that decision-making for each family is made in their best interests and following clear communication
- providing strong clinical leadership and engagement within each unit and throughout the network
- ensuring that family-centred care is provided by an expert and highly skilled workforce
- building a partnership between commissioners and providers supporting neonatal care on a “whole pathway” basis integrated with other pathways, including those for maternity care, specialist obstetric and foeto-maternal medicine and children’s care
- providing a system where care is given as close to home as possible
- auditing services to allow them to measure and publish clinical outcomes
- clinically managing strategies that are underpinned by research.

The government has asked each region and network to develop implementation plans for how they will achieve better neonatal services by March 2010.

“We recognise that the economic climate

is not necessarily ideal for changing policy, but I am optimistic as it is the NHS who wanted this toolkit and who have driven it,” says Ms Binns. She places the greatest emphasis on commissioners assessing where their neonatal services are and what their priorities are.

“They need to ask themselves what they can do quickly, what they can do to improve efficiency and what they can do in the longer term,” she explains. “Look at what everybody does and what skills are needed to do the job and who can be trained up, look at what skills and competencies are needed rather than historical education.”

Tina Pollard, clinical service manager for neonatal service at Addenbrookes hospital in Cambridge, agrees, but warns that because babies as patients are not voters they often get pushed to the back of the queue in terms of the services they receive.

“Babies are not mini adults, they are not even mini children, they are unique and we cannot assume that they do not require the same amount of care as adults,” she says. “As chair of the Neonatal Nurses Association I know that quite a lot of colleagues feel beaten or don’t know where to start in trying to improve services. There is a huge issue for the NHS around leadership, empowerment and decision planning to get the improvements that are needed.”

Success in neonatal services will mean better outcomes for babies and their families coupled with the right care provided as close to home as possible on the majority of occasions. To achieve this there need to be well thought-out pathways of care between neonatal units, paediatric units and maternity services across the country to deliver equitable care.

“It is good to give babies the best start in life to avoid long term future health problems that will cost the NHS much more to treat,” says Ms Binns. ●

To access the DH Toolkit for High Quality Neonatal Services go to www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107845



HOSPITAL ADMISSIONS

THE PATIENT WAY TO CARE FOR KIDS

Children in hospital cannot be treated in the same way as adult patients and this must be considered when deciding the most appropriate setting to look after them

"Children should be in hospital only if they have to be. There has to be as much care provided in their home or in the community as possible in order to help them grow and develop as a normal child would," explains Liz Morgan, professional adviser on nursing, children and young people to the Department of Health. Despite this, the attendance at hospital and subsequent hospitalisation of children is still rising.

The government's National Service Framework for Children, Young People and Maternity Services, published in 2004, states that clinical assessment of the ill child

requires skill and experience. It continues: "Re-assessment after a period of observation or after initial treatment is often essential. In any single illness episode, where possible, the referral should result in an assessment by staff who are more senior/experienced in clinical care of children than the person making the referral."

Ultimately, children have different needs from adults, and hospitals must take this into account in order to provide safe and child friendly care.

Nearly 50 years ago, *The Welfare of Sick Children in Hospital* report, more commonly

known as the Platt report, was published. It focused on the fact that children in hospital cannot be treated in the same way as adult patients.

The Parliamentary committee that investigated the care of children in hospital, chaired by Sir Harry Platt in 1959, found that hospitals were miserable places for the young, where they were expected to conform to ward routines and not allowed to play. To lie quietly was the accepted norm, and under no circumstances were the parents allowed to visit outside the declared visiting hours.

Children, particularly infants and younger children, suffer from a different range of diseases and disorders from those commonly seen in adults and have different anatomy and physiology, which change as they grow. Their skills in communication

CHILDREN'S COMMUNITY NURSING

According to the National Service Framework, children's community nursing teams are "essential to support the care of children and young people who require healthcare outside a hospital setting".

They need to provide support to children, young people and their families, responding to local needs, and prevent hospital admission where appropriate, facilitate early discharge, and care for children with complex needs.

"Ideally, these should work across a number of settings, for example, hospital, home and school, improving continuity and maximising the available skills."

Liz Morgan, professional adviser on nursing, children and young people to the Department of Health, says that in order for ill children to remain at home with access to community service they need the support of a children's community nursing team.

"A community nurse is the one professional everyone, from families to the voluntary sector, mentions; for the ill child, a children's community nurse co-ordinates care and is fundamentally important to that care," she says. "The service needs to be accessible to children and their families when they need it, not just Monday to Friday 9am to 5pm."

Ms Morgan warns that at present there is not enough community nursing provision in the NHS to meet need: "I recognise that this is a difficult economic climate but if we want to see serious transformation of healthcare for children then there needs to be an acknowledgement that care provided at home is the direction of travel and to do that we need the resources in the community."

"At the moment a lot of areas have a service of sorts and some areas don't have a service at

all. We also don't have data on community health services for children."

She adds: "It is up to commissioners to find out what they have got."

She explains that community nursing teams can also provide better value for money.

"We do know, for example, that to keep a child in an intensive care unit bed costs the NHS £2,000 per day.

"However, if they were cared for at home with a ventilator and a team of nurses and their parents it would cost £500 a day, so there is a big difference.

"Commissioners have not really taken that on board yet. They need to look at the total package."

DH guidance on children's community nursing roles states:

- A team of nurses may provide both emergency care and triage alongside other emergency care staff, together with support for acute illness in the ward, paediatric assessment unit or at home. The team can reduce first admissions, the duration of admissions, second admissions for the same problem, and second attendances at outpatient follow-up. In some areas, this is described as a "hospital at home" service
- Community children's nurses may provide care and support for children and young people in the community with long term disorders as well as for those with palliative care needs
- Community children's nurses may adopt "consultant" roles for caring for children and young people with particular conditions. Emphasis needs to be placed on supporting their development and ensuring that they receive sufficient on-going training and updating in their field of expertise.

'Services treated children as if they were simply "mini adults", needing smaller beds and smaller portions of food, and made little effort to tailor explanations to their understanding'

and their ability to choose and consent to treatment are different. They are also more vulnerable to intentional harm than many adult patients.

A number of reports have raised concerns about the quality and safety of services for children in hospital. The inquiry into the death of Victoria Climbié found that established good medical practice and straightforward procedures on how to respond to concerns of deliberate harm to a child were not followed. It called for staff to be trained adequately to carry out their duties in the care and protection of children.

Professor Sir Ian Kennedy's report into events surrounding the deaths of children

who underwent heart surgery at the Bristol Royal Infirmary found that the quality of care was less than it should have been, services were fragmented, the rights and vulnerability of children were overlooked, and open and honest relationships with children and parents were lacking.

Services treated children as if they were simply "mini adults", needing smaller beds and smaller portions of food, and made little effort to tailor explanations to the understanding of children or their parents. Staff were skilled in treating adults but had no specific training in treating children, and facilities were designed with little acknowledgement of the needs of children.

Ted Wozniak, professional adviser to the DH on paediatrics, says that the NHS is still falling short in terms of the skills and competencies needed by its staff to assess sick children.

"GPs have often not got the skills in terms of assessment and in safeguarding," Dr Wozniak says. "There needs to be longer training in this area. GPs need access to paediatric specialities in their training."

"There are some areas of the country where most GPs are getting access to paediatric training, but in some areas this is less than half of all GPs. Having a workforce able to recognise illness in children really is a key step."

Dr Wozniak says that if staff need to be working at a senior level to assess sick children this will have ramifications on where care is provided.

"If they have to be medically trained to a senior level then we will have to centralise some children's specialist services. We need networks of children's health services and managers need to understand that these will only work if we pull patients through the system and back again. We need to be able to discharge children from specialist centres back to district general hospitals as soon as possible, this is something NHS managers at a hospital level need to understand," he explains.

Ms Morgan agrees and says that it is important for the NHS to invest in getting the services right.

"This means ill children getting help at the time they need it, managing their conditions appropriately will also be better for the public purse," she says.

"As a country, we have signed up to the United Nations convention on the rights of the child and there is a government drive to say that we want England to be a world class place to grow up," adds Ms Morgan. "All of the parties involved in children's services need to work closely together so that education is integrated with social services and health. We are making progress on this, but there are still a lot of systematic and procedural things that are standing in the way."

She highlights the children's trust model as something that has great potential for improving the services for children, particularly focusing on the areas where primary care trusts and local authorities need to work together, for example, in the area of avoiding hospitalisations and supporting children at home and at school.

According to the National Service Framework, primary care trusts and NHS trusts must ensure that all children and young people presenting with undifferentiated illness in any location are seen by competent staff who are trained to assess children: "Services must ensure that staff of sufficient seniority and relevant

KEY FACTS – CHILDREN'S ACCESS TO NHS SERVICES

- 25 per cent of family doctors' workload is with children
- 90 per cent of children see their family doctor each year
- On average, a child sees their family doctor 3.5 times a year
- One in 12 children under the age of five are admitted to hospital each year
- By their third birthday, one in four children will have experienced an acute admission
- After the age of five, approximately one in 12 children are admitted each year, with over half of such care being provided by the surgical specialities
- Each year, one in five children attend an accident and emergency department, mostly with accidental injury, but about one-fifth with a non-traumatic disorder

experience are available to take rapid and effective decisions.”

It states that local audits should ensure that, at each level of assessment, children and young people with potentially serious illness who need to progress to the next level of care are accurately identified.

It continues: “Every assessment [must] result in a clear management plan in the patient record, based on evidence-informed protocols, guidelines and pathways. Services [should] ensure that when a child or young person does not require admission to

hospital, the parents are fully involved in the development of the care plan, which includes the criteria for when to contact somebody again, who to contact, where and how. At the end of an assessment, there [should be] a written communication to relevant professionals involved with the child’s or young person’s day-to-day care and to the parents when appropriate.”

According to national clinical director for children, young people and maternity Sheila Shribman, the NHS must do more at the front line to spot sick children.

“I am very keen to see more training for GPs and we need to get the incentives right, for example in terms of the quality and outcomes framework, or accreditation, or revalidation and child health,” Dr Shribman says. “We must look at quality and productivity and resource utilisation in this area. It is not a good idea to hospitalise children if they don’t need to be. It is about having staff with the skills and competencies and the confidence to tackle short and long term childhood illnesses, both physical and emotional,” she adds. ●

SPOTTING THE SICK CHILD

An updated version of the online educational tool “Spotting the Sick Child” has been developed to improve the delivery of emergency care to children. It includes the presentation of swine flu and other conditions with which it may be confused.

GPs and practice nurses are often the first to come into contact with sick children, and this tool aims to help them to avoid misdiagnosis.

The updated version – commissioned by the Department of Health and supported by the Royal College of Paediatrics and Child Health and the Royal College of Nursing – features video and audio guides, learner interaction and personalised performance tracking. It has also been developed for use by hospital doctors, health visitors, paramedics and ambulance technicians, and medical students.

The website is only available to healthcare professionals.

Monica Lakhanpaul, consultant paediatrician and a senior lecturer at the University of Leicester, helped design the updated tool. She says health professionals must be sufficiently skilled so that they feel more comfortable with risk taking and can feel confident in making decisions about the sick child, whether they are in or out of hospital.

“Health professionals need to be [able] to not only recognise the sick child but also the ones who can remain at home and be watched,” says Dr Lakhanpaul. “I think there is a fear that once a child is seen they will not be seen again, and therefore people admit them. We need a system in the community where children can be repeatedly observed and we need to empower families on the management of the child.

“Spotting the Sick Child goes some way to support the training of frontline staff. I think this tool should be bought by all PCTs to train their staff and, if possible, become part of mandatory training and revalidation.”

FOR MORE INFORMATION

Spotting the Sick Child

www.spottingthesickchild.com

National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill, Standard 6

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4867896

Healthy Lives, Brighter Futures www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094400

Tailored training:
assessing children
requires different
approaches from
those used with
adults



THE MISSING GENERATION

Young people are being lost from healthcare during the transition between paediatric and adult services, but many policy makers and practitioners are still unsure about what should be done and how to go about implementing changes



Mixed messages: age appropriate services for adolescents have typically been squeezed between child and adult care

The specific health needs of adolescents have been recognised for many years in the UK and have received significant impetus recently with the publication of the standards of the children's national service framework in 2004.

The *You're Welcome* quality standards for adolescent health services published in 2005 also provide a useful framework for both auditing current services and developing new services. However, much more still needs to be done.

Up to 20 per cent of adolescents have a significant ongoing healthcare need related to a long term health condition. With rapidly evolving medical technology and improvements in therapies and medical care there are increasing numbers of young people with long term illnesses or disabilities surviving into adulthood who previously would have died in childhood.

Despite this, there is evidence of the need across the NHS to develop services for adolescents. Furthermore, there is limited provision of dedicated adolescent inpatient units to support such services.

Unmet mental healthcare needs for young people aged 16 to 19 have also been reported by professionals from mental health, social, education and non-statutory services.

Adolescence is a time of rapid cognitive change from concrete to more abstract thinking and social and behavioural development. Using modern imaging and functional techniques, research is starting to demonstrate how changes in neurological structure and function relate to developmental changes, and how areas of the brain responsible for executive control and decision-making continue to mature until the mid-twenties.

Although behaviour and choices should be understood within their social context, greater understanding of neurological development may improve our ability to understand young people's perspectives and better engage with them about the health choices they make.

Understanding these changes and their impact on behaviour and cognition is important not only for those who work with adolescents, but also for parents and carers and young people themselves.

Sheila Shribman, national clinical director for children, young people and maternity, says an essential area for the NHS to address in its provision for adolescents is that of transition services for moving from children's to adult health services.

"We often lose young people from the service when they are moved from paediatrics," she explains. "Young people with diabetes for example are often lost from NHS services and then reappear in their late twenties with complications," she says.

She underlines the importance of services being provided in transition rather than in a simple transfer at a single point.

"We need to be mindful that we are not placing young people in a service with lots of older people with the same condition, we need bespoke services for young people – something the NHS has traditionally not been good at," Dr Shribman adds.

Evidence shows that, in some of areas of

YOU'RE WELCOME – QUALITY STANDARDS

All young people are entitled to receive appropriate health care wherever they access it and, to that end, the government has developed the *You're Welcome* quality criteria for all adolescent services, which lays out principles that will help health services – both in the community and in hospitals – to "get it right" and become young people friendly.

This includes NHS and independent, primary, community, specialist and acute services, as well as services that are subcontracted to provide health services to young people.

It is also important to ensure seamless service delivery to young people, through effectively joined up services across health, local authority, community and voluntary and private sectors. Services in all primary care trust areas need to take young people's needs into account. This includes primary, community, specialist and acute services.

The quality criteria have been endorsed by the Royal College of Nursing, The National Youth Agency and Brook. The criteria support the implementation of the National Service Framework for Children, Young People and Maternity Services and build on the Royal College of General Practitioners' initiative *Getting it Right for Teenagers in Your Practice*, which has been supported by the government's teenage pregnancy unit and the Department of Health.

The quality criteria cover 10 topic areas:

- accessibility
- publicity
- confidentiality and consent
- the environment
- staff training, skills, attitudes and values

- joined-up working
- monitoring and evaluation, and involvement of young people
- health issues for adolescents
- sexual and reproductive health services
- child and adolescent mental health services.

The criteria are based on examples of effective local practice working with young people aged under 20. They should be applied to general and acute health problems, and long-term disease management, such as specialist care for asthma and diabetes, and health promotion.

The aim of the criteria is to improve acceptability, accessibility and quality of services for young people and therefore choice. *You're Welcome* has been included in the 2010-11 NHS operating framework and highlighted in the government child health strategy *Healthy Lives, Brighter Futures*.

As well as providing guidance to individual services to help them meet the needs of their patients and clients, *You're Welcome* aims to help local areas achieve their priorities as identified in local strategic partnerships, local area agreements, and primary care trust and children's trusts' local development plans. *You're Welcome* can contribute to a number of objectives in the national indicator set five for local strategic partnerships and vital signs six for PCTs.

FOR MORE INFORMATION

You're Welcome quality criteria

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073586

'Services for adolescents need to be distinctly different from adult services, because young people are distinctly different from children and adults'

the country, up to 70 per cent of young adults with diabetes have no medical follow-up after leaving paediatric care and are therefore potentially subject to higher rates of disease related complications.

In one UK study of a patient cohort two years after being transferred, only 51 per cent of these patients were still attending the adult service, compared with 92 per cent attendance two years before being transferred.

Transitional care is a pivotal element of adolescent healthcare, irrespective of the presence or absence of long term illness or disability. Hopefully, all young people will make the transition from childhood to adulthood, and along the way move from the family home to live independently, from school to further education, training and work. They will also make the transition from paediatric to adult services, including

healthcare. Many young people make these journeys successfully. Some, however, will find them difficult for various reasons; and this group may include young people with long term illnesses and disabilities.

Although there are many compelling arguments that something needs to be done about transitional healthcare service provision in the UK, many practitioners and policy makers are still unsure what should be done and how to go about implementing such changes.

According to Janet McDonagh, clinical lecturer in paediatric and adolescent rheumatology at Birmingham Children's Hospital's Institute of Child Health, a useful phrase to bear in mind for transitional healthcare is that adolescence is a "stage not an age".

However, she warns that the lack of consensus with respect to age criteria between providers and policy makers only serves to confuse the area even further.

Although the National Service Framework for Children, Young People and Maternity Services, the Children's Trusts, and the Connexions strategy address the needs of young people up to the age of 19, many paediatric services still have a cut-off criteria at the age of 16. This is often in the absence of age and developmentally appropriate health services available to undertake the care of the adolescents who are between 16 and 19 years old.

‘This period of late adolescence and young adulthood is often at risk of becoming a twilight zone with young people falling out of paediatrics but not yet entering into adult healthcare services’

There is a disproportionate prevalence of disadvantage reported in the 16 to 25-year-old group – the age band where many of the healthcare transitions are likely to take place.

However, the definition of youth by both the European Union and the World Health Organisation goes as far as to include the “invisible early twenties” and there have been recent calls from psychologists to recognise this stage as another period of adolescent development – that of “emerging adulthood”. This is given particular resonance in light of the sociocultural shifts that serve to delay many of the normal adolescent transitions.

This period of late adolescence and young adulthood is often at risk of becoming a twilight zone with young people falling out of paediatrics but not yet entering into adult healthcare services.

“Adolescent services need to be distinctly different from adult services because young people are distinctly different from children and adults,” Dr McDonagh says.

“There is real confusion about the difference between transition and transfer and the message is difficult to get across even to clinicians,” she adds.

According to Dr McDonagh one-third of all organ transplants in young people run into problems when young people make the transition from paediatric to adult services.

“Children and adult services need to be considered together rather than separately in terms of costing; it is really important economically in the long term to tailor services to young people as well as adults and children,” she warns.

Dougal Hargreaves, DH clinical adviser on working with children and young people, agrees.

“Appropriate services for adolescents have not always been there, they have been squeezed between paediatrics and children’s healthcare services and adult services,” he explains.

Dr Hargreaves says there is a lot of variation in the services across the country and warns that commissioners can find it quite a complicated area.

“Adolescents don’t have a lot of services designed for them. This is not about spending a lot of money but about changing the culture in the NHS.

“Commissioners should use the *You’re Welcome* criteria as a starting point for changing the services they offer,” he says. ●

CASE STUDY: SELF-HARM



Self-harm is a broad term that can be used to describe the various things that young people do to hurt themselves physically. According to the Mental Health Foundation it includes cutting or scratching the skin, burning, branding with cigarettes and lighters, scalding, an overdose of tablets or other toxins, tying ligatures around the neck, punching oneself or other surfaces, banging limbs and the head and hair pulling.

The term self-harm is also sometimes used to describe behaviours that may be culturally acceptable yet lead to self-inflicted physical or psychological damage, such as smoking, recreational drug use, excessive alcohol or body enhancement.

However, the focus of NHS mental health services set up for those young people who self-harm is based on the foundation’s definition. In this sense self-harm refers to: “Any deliberate, non-suicidal behaviour that inflicts physical harm on one’s own body and is aimed at relieving emotional distress.”

Up to 14 per cent of adolescents will self-harm at some time, and between 20 and 45 per cent of older adolescents report having had suicidal thoughts.

Raphael Kelvin, professional adviser to the Department of Health on children’s and adolescent mental health services, says children who self-harm are on a “spectrum” – there are different types of self-harm.

“There are some kids who will cut themselves once, this is risky experimental behaviour, but they are not deeply distressed and specialist services don’t necessarily need to see them,” Dr Kelvin explains.

“As you move along the spectrum there is the young person who might cut, for example, a few times in their life, but it is not risky and they don’t do anything that is life threatening. They should be assessed and the youngsters’ stress taken note of, but it may just be a

transient adjustment or phase and they can get over it with appropriate support and advice. They do not necessarily need to come through a specialist service; careful assessment is important here, to decide who is at risk, and who is not, and the level of intervention needed.

“As you move further along the spectrum, there is the third level, somebody who is self-harming, doing inherently risky things such as overdoses and/or thinks their life is not worth living and might want to die. They should be referred to a specialist service.”

Dr Kelvin says NHS services available to those who self-harm varies across England.

“Although self-harm is more understood and there is better knowledge about the fact that young people do self-harm and its nature, this is probably not universal,” he says.

“There are still some weaknesses in education and training of the whole workforce [about self-harm], which needs to improve. All health professionals need the skills to recognise and better understand self-harm and the commonly associated mental health problems and social problems.

“For example, there are some accident and emergency departments where staff find themselves under considerable pressure and they, for whatever reason, give less than ideal services to people who self-harm. It may be because they see it as self-inflicted, or perhaps they don’t have enough time for people who self-harm. They also need to have robust effective links with specialist child and adolescent mental health advice and assessment on a 24/7 basis.”

Dr Kelvin warns “Despite helpful recent development of these child and adolescent mental health services, further development would be helpful, particularly bearing in mind links and continuities with adult mental health problems and risks.”

A LONG AND WINDING ROAD

A lack of collaboration between services remains a barrier to giving children with long term conditions the best possible chance at a normal life



The ultimate goal for many children with long term conditions is to be able to manage their illness in such a way that they are able to fully enjoy and achieve in their lives, and make a positive contribution. Their care and treatment should enable them to do that.

The National Service Framework for Children, Young People and Maternity Services says that children and young people with long term conditions, along with their families, should have the opportunity to be supported in managing their long term conditions.

To achieve this, they should have access to services that help them to develop the self-confidence and self-management skills needed to deal with the impact of their condition on themselves and their family or

carers. These services may be similar to those run under the expert patients programme for adults.

There is a lot happening nationally and locally in disease management. *Healthy Lives, Brighter Futures*, the child health strategy, highlights the need to do better in supporting people with long term conditions.

Improving care for children and young people with long term conditions in primary and community settings is also part of achieving the Department of Health's target for reducing emergency bed days and offering a personalised care plan for the most at-risk vulnerable people.

However, it is up to primary care trusts, working with local authorities and other

'Diabetes, asthma and epilepsy are common and the NHS needs to support children with these and other long term conditions, as well as helping them to support themselves'

WHAT SHOULD PCTS BE DOING FOR CHILDREN WITH LONG TERM CONDITIONS?

- The emotional wellbeing of the child, young person and their family should be regarded as an integral part of service provision.
- Hospital departments and clinics should synchronise their appointment systems so that families make a minimum number of visits to hospital. Where multiple appointments are required these should happen on the same day wherever possible. Health services should also maximise offers of appointments in school or community settings where appropriate.
- Health and local authority services should develop joint local protocols for managing the needs of children and young people with a long term condition in the school or college environment, including the management of transitions between schools.
- Primary care trusts and NHS trusts should collaborate with local education authorities to benefit children and young people in terms of achieving their health and wellbeing.
- Look at services for children and young people and examine a range of data sources and consider improved community support and the reduction of hospitalisation.
- Seek the views of children and young people and their families as they develop increasing expertise in their condition. Encourage this through the provision of education, information and support.

'A lot of discussion about long term conditions is about adult afflictions like heart failure and chronic obstructive pulmonary disease, whereas the profile of long term conditions in children is different'

partners, to agree plans that will support delivery of the national target on supporting people with long term conditions, including children and young people.

"A lot of discussion about long term conditions in the NHS is about adult conditions like heart failure and chronic obstructive pulmonary disease, whereas the profile of long term conditions in children is different," explains Sheila Shribman, the government's national clinical director for children, young people and maternity. "We have a critical mass of children with long term conditions in England and more could and should be done to address their needs."

"Diabetes, asthma and epilepsy are common long term conditions for children and the NHS needs to look at what it is doing to support children with these and other long term conditions, as well as helping them to support themselves," she continues. "PCTs, for example, should be working with local authorities to help support these children in their school environment. For children with diabetes, we need to look at how they can access multiple injections of insulin and the correct diet at school."

Dr Shribman says that the NHS is not doing well in this area compared with other countries.

"If we don't get this right now we are stacking up problems for the future," she adds.

Much can be done to help children and young people with long term conditions experience an ordinary life. A key element of this support should be helping them with their emotional wellbeing.

Children and young people who have either an acute or a prolonged illness are often at risk of missing out on educational opportunities because of lengthy absences from school, either as a result of ill health or because of frequent attendance at clinics and hospitals.

At a local level, PCTs and local authorities need to address a range of issues to ensure health and education services work together in a supportive, co-ordinated way to help children and young people to develop and achieve their full educational potential.

This includes establishing processes for effective communication about the short and long term needs of an individual child. It also means supporting the re-integration of that child back into school after treatment for illness or injury.

TOWER HAMLETS AND WHIZZ-KIDZ

Wheel spin: Whizz-Kidz has provided mobility equipment for more than 100 children in Tower Hamlets



In April 2008, Whizz-Kidz began working with Tower Hamlets Primary Care Trust to meet the seating and mobility needs of all children and young people with disabilities aged from birth to 26 years old.

To date, the team has provided more than 100 children with mobility equipment including buggies, manual wheelchairs and powered wheelchairs.

With an average of 30 face-to-face contacts a month, Whizz-Kidz has managed to all but eradicate a waiting list for children and young people awaiting assessment or review of their equipment needs across Tower Hamlets.

All patients referred for new episodes of care are now guaranteed the offer of an appointment within four weeks of receiving the referral, with most appointments actually being offered within two weeks.

From 2009, Whizz-Kidz also agreed with the PCT that, wherever possible, it would provide

equipment to meet the needs of those children and young people requiring a wheelchair or buggy for a short period, either due to elective surgery or trauma. So far it has provided wheelchairs to 13 children, 11 of whom are not normally wheelchair users.

Whizz-Kidz also works in schools in Tower Hamlets and has been running regular clinics within the three main special educational needs schools that cater for most children and young people with disabilities in Tower Hamlets. The charity has also organised wheelchairs skills training courses for users.

Whizz-Kidz chief executive Ruth Owen says that although the government has done much to improve services to children with long term conditions and disability, more can be done.

"We still need to improve how long it takes for children to get wheelchair access, there is a lack of focus and expertise in the NHS in this area. Many experts still think that children



under five don't need to be independent in a wheelchair. This is wrong. We need to ensure that disabled kids remain high on the agenda and that paediatric mobility is seen as important."

She says that in Tower Hamlets the model works well and the charity is now looking at providing the service across other PCTs in London.

"It is about convincing NHS managers to invest in this.

"In Tower Hamlets, for 70 per cent of children we see, we get the child into a wheelchair the same day. Some kids can wait up to 10 years with other PCTs and get nothing.

"Going forward, the NHS knows that money will be tighter so they may look to us as we can offer better value for money, we know our business and have our own model of wheelchairs and we can often save the NHS between £50,000 and £100,000," she says.

Social services should be able to provide support to a child or young person and their family to ensure that parents or carers are enabled to continue providing the level of care that their ill child requires.

Children and young people must be helped to understand their illness and to make critical decisions, as well as ensuring that their wishes and feelings are taken into account in the decision-making processes.

The NHS must help to develop systems to ensure that health services provide information, training and support to schools and early years settings, in caring for children and young people with medical needs. The needs of young people attending college and university also need to be considered at the local level.

The children's national service framework warns there is evidence that children living in disadvantaged areas or communities are more likely to have increased absences from school due to poor health, which will contribute to a cycle of poor education, low paid employment and ill health.

Dougal Hargreaves, DH clinical adviser on children and young people, says that the provision of services in the NHS for children with epilepsy as a long term condition varies widely across England.

"First, there is a 20 to 30 per cent rate of misdiagnosis, which costs the NHS between £50m and £160m; some of that is about the training of healthcare professionals, but it also is a lot about the existence of networks of care," Dr Hargreaves explains.

He adds: "Children with epilepsy need to be treated in the appropriate part of the health service. The National Institute for Health and Clinical Excellence has given clear guidelines on the need for specialist epilepsy nurses who can help the child or young person and give appropriate advice to their school."

However, he says this level of provision is variable.

"Improvement in training is a big issue. General paediatricians need the skills and knowledge to provide a good quality local service and refer appropriate cases on to a specialist," he says.

Another area the NHS needs to consider is that of genetic diseases. Sickle cell disease is now the most common single gene disorder detected in children. Across England, as a result of newborn screening, about 350 affected children are detected each year.

This long term condition requires expert support, for example, to prevent strokes and

'Improvement in training is a big issue. General paediatricians need the skills and knowledge to provide a good quality local service and refer cases to a specialist'

CHILDREN WITH INCONTINENCE

There are at least 500,000 children who suffer from nocturnal enuresis and a significant number troubled by daytime wetting and faecal incontinence, yet services are fragmented and often made up of a collection of professionals providing different levels of intervention in both the community and hospital.

There are big gaps in service provision, some inappropriate specialist referrals and some money wasted in providing products instead of expertise. However, there are other cases where expert advice is not available and children and young people therefore are missing out.

Incontinence is distressing for children and young people and can be indicative of both physical and emotional problems; it can lead to bullying at school and cause emotional and behavioural problems.

The government document *Good Practice in Paediatric Continence Services – Benchmarking in Action* sets out an essence of care benchmarking best practice tool that can be used to help develop services.

An integrated community-based paediatric continence service, informed by the good practice guidelines, can help to ensure that accessible, high quality assessment and treatment is provided to children and their parents and carers in any setting.

A clear care pathway for children with continence problems needs to be developed at a local level.

to monitor the condition. But alongside this, much better co-ordinated local support – including expert nursing, social and psychological help – could assist families to cope with the interwoven severe painful crises, infections and other complications that many children have and so prevent avoidable hospital admissions.

Schools could also do much more to help make these children's lives happier and less stressful.

Allison Streetly, programme director for the NHS Sickle Cell and Thalassaemia Screening Programme, says that health service managers need to see genetic disease such as sickle cell and thalassaemia as a mainstream issue, rather than a minority or just a genetic issue.

"Across England, one in 35 women is a sickle cell carrier. MPs are now seeing these genetic diseases in their community and the NHS will need to respond to it," says Dr Streetly.

At present, one in every 2,000 babies in England is born with sickle cell disease compared with one in 2,500 with cystic fibrosis.

"A lot of managers do not realise how common this condition is, there has to be a clear policy on this as to what the NHS should be doing," she says.

"My main message to NHS managers is that they need to review their service provision for this condition across the whole pathway and develop better long term condition management to go alongside specialist care," she says. ●

Where to find more information

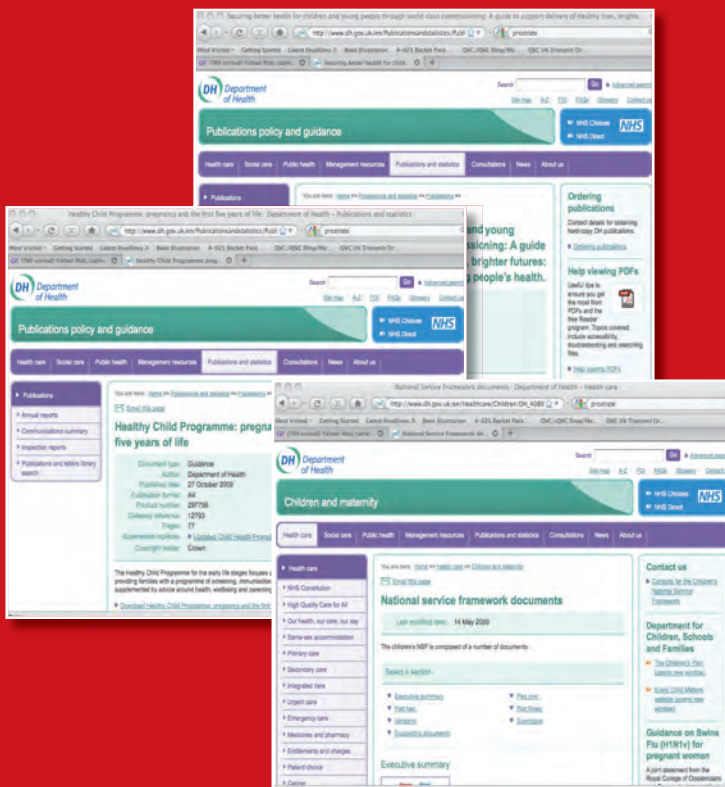
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