February 2009

Council for Disabled Children

CDC policy analysis: 'Healthy Lives, brighter futures, the strategy for children and young people's health'

Implications for disabled children

Highlights

Specific measures relating to disabled children include:

- **£340 million** NHS funding confirmed to be available over 3 years (2008-2011) for palliative care and end of life care, short breaks, community equipment and wheelchair services for disabled children and young people.
- **£30 million** of the £340 million total to be spent on **children's palliative care services**.
- A commitment that that by 2010, all children with complex health needs will have an **individual care plan**.
- A commitment to develop new commissioning models for **community equipment** for children, with a series of pilots to begin in 2009-10.
- A commitment to establish a partnership between Whizz-Kidz and the London Strategic Health Authority in conjunction with PCTs and local authorities to improve commissioning and provision of **wheelchairs**.

There is potential for disabled children to benefit from the following wider points:

- The expectation that parents should get the **information they need** to support their children's health. 'Local areas will be expected to set out what children and families can expect from their health services locally.'
- Recognition that **mental health problems** are more common among children with a learning disability.
- Commitment that the **PE and Sport Strategy for Young People** will focus on a number of areas, including 'providing more support for… children with disabilities.'
- Commitment to **re-issuing existing guidance for the health promotion of looked-after children** to place it on a statutory footing for healthcare bodies.

This note predominantly sets out *new* commitments or information that were not previously announced before publication of the strategy.

Policy context and general principles

- The Child Health Strategy states up front that it cements standards and ambitions set out in:
  - National Service Framework for Children, Young People and Families
  - Every Child Matters
  - NHS Next Stage Review
  - The Children's Plan

- Two further documents referred to throughout the strategy are:
  - Aiming High for Disabled Children (May 2007)
  - The children's palliative care strategy, Better Care: Better Lives (February 2008)

- The Child Health Strategy shows what impact the NHS Next Stage Review vision will have for children, young people and their families, and reflects the four key principles for the NHS through which the Review is being taken forward:
  - Subsidiarity
  - Local leadership/devolution
  - Clinical leadership
  - Systems alignment[1]

- Services are referenced in the following groups: universal, targeted and specialist.

- Recognition that for children in need of specialist healthcare, including disabled children, getting it right in the early years is especially important to improve quality of live and prevent future challenges.[2]

- Recognition that there are wider determinants to children's health including the home, local neighbourhood, schools and other community settings.[3]

- The government's four overarching objectives for children and young people are:
  - World class health outcomes – including reducing childhood obesity and improving children's mental health.

  - Services of the highest quality – including universal services such as schools, GPs and Children's Centres, and specialist care for children who are ill or with long-term conditions.

  - Excellent experiences of services for children and parents – more convenient support and tailored to individual needs.

  - Reducing health inequalities – through expanding services to those who are from disadvantaged groups.[4]

[1] Para 2.10
[2] Para 1.23
[3] Para 1.27

Pregnancy and the early years (chapter 3)

- There is recognition more can be done to support parents and children during pregnancy and the early years.

- The principle that parents should get the information they need to support their children's health is reinforced. 'Local areas will be expected to set out what children and families can expect from their health services locally.'[5]

- The Child Health Promotion Programme has been renamed the Healthy Child Programme. It is led by health visitors and other frontline practitioners. 'We expect to see a growing number of health visitors taking this forward, and will work with the profession to promote recruitment and ensure strong professional support for this important role.'[6] Health visitors will benefit from more targeted training including an e-learning programme.[7]

- There is a commitment to develop a new Antenatal Education and Preparation for Parenthood Programme. It will seek to improve access to high quality antenatal education and support to prepare parents for parenthood.[8]

- There is a commitment to work with the Personal Child Health Record (PCHR) National Working Group to develop the 'Red Book' – one of the ways in which parents are able to find out more and record their child's early development.

School-age children (chapter 4)

- Recognition that mental health problems are more common among children with a learning disability.[9]

- Recognition that wider environmental factors have an impact on children's ability to stay healthy. 'Even small amounts of green space are shown to have qualities that facilitate relaxation and recovery from mental fatigue and stress, particularly for those with symptoms of ADHD.'[10]

- Commitment to develop the school-age elements of the Healthy Child Programme, with an aim to publish best practice guidance in 2009.[11] Also says 'we will explore how we can deliver against an aspiration that every teenager can have access to a professional, with appropriate health skills, to talk about their health issues.'[12]

---

[4] Para 1.32
[5] Para 3.2
[6] Para 3.30
[7] Para 3.31
[8] Para 3.36
[9] Para 4.11
[10] Para 4.18
[11] Para 4.24
[12] Para 4.36

- Commitment that the PE and Sport Strategy for Young People will focus on a number of areas, including ‘providing more support for… children with disabilities.’[13]

- Commitment to enhance the Healthy Schools Programme ‘to help schools to be better able to promote both universal health improvement for all pupils and provide additional support targeted on those identified most at risk.[14]

- Commitment to re-issuing existing guidance for the health promotion of looked-after children to place it on a statutory footing for healthcare bodies. This guidance holds statutory status among local authorities but is currently non-statutory for the NHS. There is recognition that children in care may well have health needs arising from a disability or additional needs.[15]

Young people (chapter 5)

- Four Teenage Health Demonstration Sites (Bolton, Hackney, Northumberland and Portsmouth) are exploring essential elements for successful adolescent health services. There is a commitment to disseminate the learning from these sites and to support the roll-out the ‘You’re Welcome’ standards across England.[16]

- Commitment that the PE and Sport Strategy for Young People will focus on a number of areas, including ‘providing more sporting opportunities for young people with disabilities.’[17]

- Commitment to extend the principles of the National Healthy Schools Programme into the further education sector.[18]

- Expectation that there will be ‘systematic involvement of young people and their parents in service development, supported by accredited frameworks for young people’s involvement, such as ‘Hear by Right’.[19]

- Recognition that one quarter of young people in contact with the Criminal Justice System (CJS) have learning disabilities and 30% have a physical disability.[20] A health and social care strategy for children and young people in contact with the CJS is being developed.[21]

[13] Para 4.27
[14] Para 4.34
[15] Para 4.50 – 4.53
[16] Para 5.23
[17] Para 5.24
[18] Para 5.25
[19] Para 5.43
[20] Para 5.45
[21] Para 5.54

Services for children with acute or additional health needs (chapter 6)

Overarching principles

- Recognition that the high number of children's attendances in primary care highlights the need for GPs and their teams to provide age-appropriate services and have the right training and skills.[22]

- Recognition that some professionals still have relatively poor knowledge of a child's condition and that families can experience a fragmentation of services or variability in services available in different areas.[23]

- Children and families need support tailored to their needs, allowing for choice over how care is provided. They need universal services to be inclusive and responsive to their needs.[24]

- As far as possible health services should be provided in a way that minimises disruption to family life and the child's wider development and their participation in education and social activities.[25]

- The current approach to providing services to children with acute or additional health needs has 4 principles: high quality, personalised, participation and feedback and information and transparency.[26] This is in line with the Aiming High for Disabled Children Core Offer.[27]

Information

- Expectation that Children's Trusts work together to ensure they make information available on the local services offer.[28]

Skills and roles

- Commitment to develop models of best practice to support commissioners and providers to improve services for children and young people who need urgent and emergency care. One specific area to be covered is children and young people with complex needs.[29]

- Recognition that there is variability in how children with long-term conditions are supported in school, with a 'failure' in some areas of education and health services working together.[30]

---

[22] Para 6.6
[23] Para 6.10
[24] Para 6.11
[25] Para 6.12
[26] Boxed text page 67
[27] http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer/
[28] Para 6.30
[29] Para 6.33
[30] Para 6.34

- Commitment to update and reissue guidance 'Managing Medicines in Schools' and an awareness-raising campaign. This will include guidance relating to children with complex health needs and clear expectations of partners including schools and PCTs.[31]

- Recognition of the central role played by Children's Community Nurses for disabled children and those with complex health needs. Expectation on commissioners to develop these services to provide 'all-round' care packages including end-of-life care, 24 hours a day, seven days a week in the location preferred by the family.[32] Commitment to work with health staff to develop 'community children's service', with nursing as central component.

Personalising care

- Defines personalised care for children and families as care 'delivered as close to home as possible, working across service boundaries, delivering age-appropriate services, engaging children and parents in the design of services and a voice in the assessment of services.'[33]

- Emphasises care close to home should maximise education and social and developmental activity and that multi-disciplinary teams should extend to education as well as social care.[34]

- Recognises that children with long-term conditions have increased rates of mental health problems.[35]

- Promises that by 2010 all children with complex health needs will have an individual care plan, building on the existing Common Assessment Framework, the Care Programme Approach used in CAMHS and the roles of key workers and lead professionals. There will be pilots to test and evaluate the new ways of providing better-integrated care as part of the NHS Next Stage Review. There is also recognition that 'plans for personalised budgets can offer parents more control over decisions on their children's care' – but no commitment to take forward specific work in this area.[36]

- Commitment to promote the development of self-management programmes for children through the voluntary sector and social enterprise and encourage local areas to assess how these can be made available to their local areas.[37]

Service re-design (commissioning)

- Recognition that commissioning arrangements will need to be differentiated according to numbers of children and area to be covered. Example given is

[31] Para 6.36
[32] Para 6.38
[33] Para 6.40
[34] Para 6.41
[35] Para 6.41
[36] Para 6.42
[37] Para 6.45

where there may be specialist services for small groups of children with complex needs that may need to be commissioned across larger areas than the PCT. [38]

- Commitment to prioritise work to improve commissioning of equipment for disabled children. This will include action to develop a more responsive market for community equipment for children and a series of pilots in 2009-10 to develop commissioning models.[39]

- Commitment to improve joint commissioning and provision of wheelchairs for children, through a partnership between Whizz-Kidz and the London SHA, building on the successful Whizz-Kidz / Tower Hamlets PCT partnership.[40]

- Commitment to fund the Autism Education Trust to make support for local authorities and PCTs to improve the commissioning of services for children with autism a priority for its work in 2009-10.[41]

Services for disabled children and those with complex health needs

- Confirms that £340 million NHS funding is available over 3 years (2008-2011) for palliative care and end of life care, short breaks, community equipment and wheelchair services for disabled children and young people.[42]

- Specifies that £30 million of the £340 million total is for children's palliative care, including for capacity-building, 24 hour crisis support and short breaks in order to implement the *Better Care: Better Lives* strategy published last year. Also confirms that Ministers will continue to chair an oversight group to monitor progress of the palliative care strategy *Better Care: Better Lives*.[43]

- Children's continuing care is mentioned with reference to the consultation on a national framework – there is no further commitment around this.[44]

Access to allied health professionals (AHP) and psychological therapies

- Recognition that access to AHP services such as physiotherapy and occupational therapy remains variable.[45]

- Commitment to ensure that [the improved AHP offer] explicitly addresses the accessibility and quality of AHP services for children. The offer has 3 components: 1) collection of referral to treatment data 2) encouraging self-referral to AHP services 3) ensuring quality metrics are inclusive of AHP

[38] Para 6.51
[39] Para 6.54
[40] Para 6.55
[41] Para 6.56
[42] Para 6.61
[43] Para 6.62
[44] Para 6.63
[45] Para 6.67

contribution. The government will work with SHAs who have identified this as a priority issue as pathfinders and share the learning nationally.[46]

Making it happen: system-level transformation (chapter 7)

- Recognition that 'there is substantial variation in the form and effectiveness of Children's Trusts across England, and that, while some progress has been made to encourage better co-ordinated working between organisations, more needs to be done.'[47] Also outlines legislative plans to put Children's Trusts on statutory footing and to extend ownership of the CYPP to all partners, including health bodies.

- Expectation of senior-level representation from the PCT on the Children's Trust. The CYPP will contain agreed plans to address the health needs of children and young people, reflecting shared priorities in PCT plans and Local Area Agreements, 'including the most vulnerable and those with additional health needs.'[48]

- Recognition there are 'practical obstacles' to developing robust joint plans for areas of overlapping responsibility such as services for disabled children.[49]

- Commitment that DCSF and DH will 'develop guidance that will set out in detail how the new arrangements should work, including steps to promote transparency over resources, while also supporting the ability of local areas to innovate.'[50]

- Expectation that Children's Trust partners ensure children and families are provided with accessible and comprehensive information about what child health services, advice and support are available locally.[51]

- Expectation that Children's Trust partners will work with planners, highways officers and managers of public spaces to help them shape healthy environments for children. 'It will also be important for Children's Trust partners to consider the broad range of factors that impact on children's health, such as housing.'[52]

- Recognition of the important role of GPs. Commitment that 'once the new arrangement for Children's Trusts have settled down, we intend to identify and share best practice to make sure the work of GPs is effectively embedded in the Children's Trust.'[53]

---

[46] Para 6.68 & 6.69
[47] Para 7.10
[48] Para 7.13
[49] Para 7.14
[50] Para 7.15
[51] Para 7.19
[52] Para 7.20
[53] Para 7.26

- Recognition that at present less than 50% of GPs receive acute paediatric training experience. 'We are asking the Royal College of General Practitioners (RCGP) to consider … whether training around child health needs should be given greater prominence.'[54]

- Recognition that the indicator sets that underpin the measurement of national priorities are of central importance to LAs and PCTs. Both the National Indicator Set and Vital Signs are referenced, with an expectation that 'PCTs and local authorities will identify their shared priorities that meet the needs of local people.'[55]

- In order to improve the quality and use of data relating to children and young people's health, there is a commitment to:

  - Establish a long-term role for the Child and Maternal Health Observatory (ChiMat)
  - Test, with a view to roll-out, minimum NHS datasets
  - Develop a model to understand the relationship between health spend and health outcomes on children… particularly those relating to complex needs (the disabled children's indicator is referenced)
  - Work on providing better data on experience and outcomes
  - Publish best practice on data collection (Aiming High for Disabled Children is referenced)[56]

- Challenges of information-sharing recognised. Commitment for DCSF and DH to work with Together for Children 'to develop a programme of support that will enable more appropriate and effective information sharing locally. This will be rolled out from spring 2009.'[57]

- Recognition of the challenges around workforce – including pressures points around paediatrics, maternity services, neonatal services, health visiting, school nursing and children's community nursing services. 'As part of this strategy, the DH, in partnership with SHAs, is developing workforce modelling tools that will help SHAs to consider these pressure points…[58] In particular, we expect to see expansion in the health visitor workforce.'[59]

- Recognition that 'empowering citizens' is a key driver for improved services. Expectation that there is 'a strong voice for children, young people and parents in the design and delivery of services, so that staff and services learn from their experience.'[60]

- Recognition that the Healthcare Commission (and in future the Care Quality Commission) are complimented in their roles by Ofsted. 'The government will

[54] Para 7.27
[55] Para 7.45
[56] Para 7.46
[57] Para 7.52
[58] Para 7.61
[59] Para 7.62
[60] Para 7.67

be working with these partner organisations to promote a sharper focus on children and young people's health. This will include supporting partnership and joint working between inspectorates on children's services.'[61]

Prepared by Louise Franklin
16 February 2009
E: lfranklin@ncb.org.uk
T: 020 7843 6108

[61] Para 7.73