

# Disabled children & health

## Campaign briefing from the Every Disabled Child Matters campaign

**Disabled children use NHS services significantly more than other children, yet they and their families consistently report poor experiences of both universal and specialist health services.**

**EDCM wants to see the following priority recommendations addressed by the Department of Health and Primary Care Trusts in England in order to tackle this situation:**

1. **National priority** – The **Department of Health** should inform PCTs that their annual Operating Plans will not be agreed unless they demonstrate that their spend on disabled children's services and children's palliative care services reflects national policy expectations.
2. **Local leadership** – Every **PCT** should have a named lead at a strategic level responsible for services for disabled children, including children with complex health needs and children with palliative care needs, by December 2009.
3. **System accountability and transparency** – Every **PCT** should publish information on the additional funding they have allocated locally for each financial year (2008-2011) to disabled children's services, separately identifying short breaks, children's community equipment, children's wheelchairs and children's palliative care.

## **Thank you**

Every Disabled Child Matters (EDCM) is extremely grateful for the support of **The Children's Trust, Tadworth**, which enabled us to produce this briefing, and the parents of children who use their services, who are quoted throughout. Find out more about the work of The Children's Trust, Tadworth at [www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)

EDCM would also like to thank **Adam Stafford** for his commentary throughout the briefing and **Lavinia Scott** for her illustrations. Adam and Lavinia are both young members of the Council for Disabled Children Steering Group.

Thanks also goes to **Children's Hospices UK, ACT, Mencap** and **Whizz-Kidz**, for their input.

**Written by Louise Franklin**

As a young disabled person throughout my life, I have had lots of contact with doctors and other health workers. A lot of the time this contact has ended well but sometimes not so well and sometimes very badly. When YOU get this report which is about disabled children and health, don't just put it in the filing tray, READ it, TALK about it and ACT on it.

And it's not just you that should read this briefing, make sure others who are responsible for making decisions about health policy read it as well. The EDCM campaign works hard to make sure disabled children and our families have rights, opportunities and all the services we need. I think this campaign is really important.

I would like to thank EDCM for listening to my experiences about using health services and also those of other disabled children and their families and then writing this excellent briefing. I know it will make a difference.

**Adam Stafford**  
**Young Member**  
**Council for Disabled Children Steering Group**



## Introduction

Looking after the health and well-being of the population in England through the NHS is clearly a priority for the government – described by the Prime Minister Gordon Brown as ‘a moral right to be secured for all’.<sup>1</sup> Yet historically there has been little evidence that children’s health has been a central priority.

The past two years however, have signalled a new focus in the government’s approach to children’s health. In a clear break with the past, the NHS Operating Frameworks for 2008-09 and 2009-10 explicitly state that children should be one of four national priorities for the NHS, alongside cancer, stroke and maternity.

The health and well-being of children was raised even further up the agenda with the publication in February 2009 of ‘Healthy lives, brighter futures’<sup>2</sup>, the government’s first-ever strategy for children and young people’s health.

These developments are particularly significant for disabled children, who are disproportionately high users of the spectrum of health services. Despite disabled children having the same rights as all children to access health services, all the evidence points to them experiencing unequal access to universal health services and barriers to accessing specialist and targeted health services that would enable them to lead ordinary lives.

An investigation by the Disability Rights Commission in 2006<sup>3</sup> revealed ‘an inadequate response from the health services and governments in England and Wales to the major physical health inequalities experienced by some of the most socially excluded citizens: those with learning disabilities and/or mental health problems’. It found that the least satisfied parents were usually those of children with the most complex multiple impairments. In 2008, the Healthcare Commission described the reality for disabled children and their families:

‘Children and young people with complex needs, including children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need...the funding and provision of services for children and young people with learning and/or physical disabilities varies throughout the country.’<sup>4</sup>

This briefing paper sets out the case for further action to ensure the health needs of disabled children are appropriately met.

**Note on devolution:** Health is a devolved policy area. This means there are different healthcare systems in England, Wales, Scotland and Northern Ireland. This briefing paper relates to England only. Information about EDCM’s sister campaigns in the nations is at the end of this briefing.

## Disabled children and health – the challenge and policy context

There are around 770,000 disabled children in the UK, with 570,000 of those children in England.<sup>5</sup> Disabled children aged 0–16 are the fastest growing group amongst the population of disabled people.<sup>6</sup> Over the past ten years there has been a significant increase in the number of children with complex health needs, due to the survival of pre-term and low birth weight babies and advances in medicine leading to earlier diagnosis of congenital and genetic conditions. Children also now have better outcomes and longer life expectancy following severe illness or injury. It is estimated there are around 100,000 children in England with complex care needs, who need support from a wide range of services.<sup>7</sup>

The Department of Health in 1999 estimated that there were 6,000 children dependent on assistive technology such as ventilators, tracheostomies, gastrostomies, or oxygen dependent. This figure is now likely to be significantly higher.<sup>8</sup>

It is also estimated that there are 23,500 children aged 0-19 in the UK with a life-limiting or life-threatening condition requiring access to palliative care<sup>9</sup> and 70,000 children who require mobility equipment which would support them to lead independent lives.<sup>10</sup> These trends place increasing demands on all statutory services, particularly health services.

**There are real opportunities to improve health services for disabled children**

However we are concerned not only with children with acute needs or severe disabilities. Disabled children experience unequal access to health promotion programmes, universal health services such as GPs, dentists and emergency care settings, as well as specialist and appropriate palliative care services. It is clear that a whole-system approach is needed to ensure the health needs of disabled children are being met and that they are able to exercise their right to access healthcare in line with Article 25 of the UN Convention on the Rights of Persons with Disabilities and Article 24 of the UN Convention on the Rights of the Child.<sup>11</sup>

EDCM believes that recent national policy developments present real opportunities to improve the experience of disabled children and their families in accessing and using health services.

Disabled children are mentioned explicitly in both the 2008-09 and 2009-10 NHS Operating Frameworks<sup>12</sup>, and an indicator on disabled children is included in the Vital Signs indicator set.<sup>13</sup> 'Better Care: Better Lives'<sup>14</sup> sets out clear expectations for PCTs to improve the service needed by children with life-threatening and life-limiting conditions and their families. Significantly, 'Healthy lives, brighter futures' clarified that PCTs have been allocated £340 million from 2008-2011 to improve disabled children's services, with £30 million of the total for children's palliative care.

These developments in health are bolstered by the government's three year transformation programme 'Aiming High for Disabled Children'<sup>15</sup> which focuses on local authority support for disabled children and their families.

However as is often the case, there can be a disparity between central government policy and local delivery. This is particularly the case for health matters, which have been devolved from central government control to local PCTs. Many of the underlying principles and vision set out in these recent policy documents mirror those in the 2004 Children's National Service Framework ('Children's NSF')<sup>16</sup>, yet the evidence set out in this briefing indicates that the impact of the Children's NSF in many areas has been minimal.

Therefore, whilst EDCM welcomes the government's vision and intentions for disabled children and their families, the campaign believes major challenges remain for PCTs in turning national policy into real improvements in services for families on the ground.

## Which children?

For the purposes of this briefing we use the term 'disabled children'. Disabled children are not a homogenous group. However they will all require the support of health services at some point in their lives. They may include:

- children with a long-term condition (e.g. cerebral palsy)
- children with complex health needs (e.g. uncontrolled epilepsy, osteopenia or gastro-oesophageal reflux)
- children with multiple impairments/profound and multiple learning disabilities (e.g. severe learning disability with physical disabilities and additional complex health needs)
- children with a learning disability (e.g. Down's syndrome)
- children with a physical disability (e.g. muscular dystrophy)
- children dependent on technology (e.g. children on ventilators or with tracheostomies or gastrostomies)
- children with a life-threatening or life-limiting condition (e.g. cancer or Batten Disease)
- children with a rare condition (e.g. Rett syndrome)
- children with acquired brain injury which can cause physical, cognitive and behavioural difficulties
- children with an autistic spectrum disorder
- children with sensory impairments

This is not an exhaustive list and these are not discrete groups – children may fall into more than one group. Its purpose is to illustrate the wide and varied needs of disabled children.

**Note on mental health services:** We have not included child and adolescent mental health services (CAMHS) within the scope of this briefing. However EDCM recognises the need for better access to CAMHS for disabled children.

## What does being healthy mean for disabled children?

Disabled children are first and foremost children, who have the rights, needs and aspirations of all children. They should be looking forward to healthier and brighter futures along with their non-disabled peers. The UN Committee on the Rights of the Child has found that inequality in access to health services remains in the UK, with disabled children in particular facing barriers to this basic right.<sup>17</sup>

EDCM and its partners believe that:

### **Being physically, mentally, emotionally and sexually healthy means**

- disabled children have equal and appropriate access to universal, targeted and specialist health care
- disabled children are empowered and supported to take as much responsibility for their own health and well-being as they are able to
- disabled children are supported to achieve maximum mobility and independence
- disabled children and their families have access to appropriate advice and support on their emotional well-being and mental health

### **Living a healthy lifestyle means**

- disabled children have the right medicine/clinical procedure administered safely
- school and home environments are adapted
- professionals are trained to recognise the needs of disabled children
- families with a disabled child are supported to contribute to their child's development

### **EDCM believes there are challenges in the following key areas:**

- **Accountability and transparency of health funding**
- **Access to universal health care**
- **Access to targeted and specialist health services**
- **Meeting the needs of children with complex health and/or palliative care needs**
- **System levers and inspection**
- **Transition from child to adult health services**

This briefing sets out these challenges and makes recommendations for change.

## Accountability and transparency of health funding

In general, funding for health services is not ring-fenced. There is an expectation from government that PCTs will make decisions about how to use their funding in the context of national priorities and local need.

£430 million in local authority funding for disabled children has been announced following the publication of the 'Aiming High for Disabled Children' (AHDC) report in May 2007. The vast majority of this funding is for short breaks, and the precise amount allocated to each individual local authority to transform short break services has been published.

By contrast, it has taken some time to clarify the corresponding level of additional funding available to PCTs. The Department of Health has now stated in the child health strategy that PCTs have £340 million from 2008-

2011 for disabled children's services, with an expectation that the priority areas to benefit from the funding are short breaks, community equipment, wheelchair services and palliative care. It has also confirmed that 1.23 percent of the total additional resource for PCTs over this period is for disabled children and that PCTs must prepare a 'local statement' in September 2009 setting out their actions in this area.<sup>18</sup>

**It is a challenge for PCTs to identify funding for disabled children**

Clearly this funding is not the only funding PCTs should be spending on disabled children, but it is a significant additional amount. Consequently, there is a real opportunity to improve provision in the key areas identified by the Department of Health.

However, the information from the Department of Health does not break down the funding by year. More importantly, we are concerned that many PCTs seem to find it a major challenge to identify this funding locally and that there is no consistent understanding of what is expected of them. In correspondence with the campaign, PCTs have reported that:

- they are unable to disaggregate spend on wheelchairs and/or community equipment between children and adults
- there are challenges in quantifying financial allocations for disabled children as funding is provided directly to commissioned services, including individually commissioned packages of care which vary considerably year to year
- commissioning processes for some services (e.g. wheelchairs) are on a block contract basis, which means funding specifically for disabled children cannot be identified
- the delay in the funding announcement for disabled children, including children's palliative care, meant PCTs did not identify any specific additional resource for 2008/09 or 2009/10
- whilst some PCTs expect to match their partner local authority's funding for AHDC, others do not
- they base funding decisions purely on local need

This feedback comes from a wide range of PCTs in England. It shows a lack of clear and consistent processes at a local level for ensuring funding is allocated to disabled children's services in a fair and transparent way.

This situation is unacceptable, even in the context of a devolved NHS. Parents and disabled young people need clear accountability and scrutiny structures, both in personnel and finance processes, to understand how their local PCT is delivering on the government's expectations for disabled children under AHDC and the child health strategy. Otherwise it will be impossible for families to come together to challenge underperforming PCTs and for the Department of Health to hold them to account.

### **Accountability and transparency of health funding – recommendations**

- **Transparency:** Every PCT should publish information on the additional funding they have allocated locally for each financial year (2008-2011) to disabled children's services, separately identifying short breaks, children's community equipment, children's wheelchairs and children's palliative care.
- **Scrutiny:** The Department of Health should scrutinise PCT statements in September 2009 and challenge PCTs who are not performing in line with national policy and investment expectations. The Department of Health should also make those statements public.

## **Access to universal health care**

Access to basic universal health care is essential for disabled children. Professionals such as GPs, community and practice nurses, dentists, health visitors, school nurses and midwives all have a role not just in providing effective primary care but are also often the key entry point to specialist health services. The Department of Health website sets out its expectation that 'every citizen should have the best possible access to these services'. Yet many health professionals have problems recognising and understanding children's conditions.

'Accessing basic dental care for my daughter is a nightmare. Because of her physical disability she can't get in to a dentist's surgery, and there is no understanding of her complex needs which mean she doesn't lose her teeth as other children do because she is fed through a tube – so doesn't chew. We had a dentist visit her at home once and he just stuck his hand in her mouth without even washing it first – she was extremely frightened. He didn't stay long after that!'

Gilly

## The need for training – examples

### **Understanding autism**

The National Autistic Society (NAS) has reported that whilst GPs themselves say the numbers of patients including children with autism are increasing, many feel referral processes are poor and that they lack the skills and expertise to recognise autism. The evidence bears this out. Many children with autism experience severe constipation and chronic bowel disorders, which NAS says are often wrongly dismissed by GPs as untreatable.<sup>19</sup>

Preliminary findings from a recent Action for Children consultation with PCTs<sup>20</sup> found that 43.6 percent of PCTs said that meeting the needs of children on the Autistic Spectrum is the area that they needed to improve upon the most – this was in the context of ranking six categories of types of impairment in terms of how well they are meeting local needs.

### **Recognising an acquired brain injury**

Health professionals are often unaware of the long-term consequences of acquired brain injury in children. The Children's Trust, Tadworth reports that many children who have an acquired brain injury and outwardly appear to have made a good physical recovery are discharged from hospital with little or no follow-up support. Significant but 'hidden' impairments can later emerge as a result of their injury, affecting their memory, ability to concentrate at school, communication skills and behaviour. Such difficulties will have a profound effect on these children's long-term outcomes, yet they may be written off as 'badly behaved' and risk being excluded from school.

### **Understanding Down's syndrome**

Cathy went along for a hearing test because she had been experiencing a little discomfort. It should have been a routine procedure, but the audiologist didn't know that people with Down's syndrome have short, straight ear canals. He pushed the osteoscope too far in her ear and perforated her eardrum. The perforation was irreparable and she's been wearing a hearing aid ever since.

## **Health care for children with a learning disability**

In March 2009 the Health and Local Government Ombudsman published a report that revealed 'significant and distressing failures' with the health and social care services provided to people with a learning disability.<sup>21</sup> She found that they experienced 'prolonged suffering and poor care', and some of these failures were for disability related reasons. Services were described as 'at best patchy and at worst an indictment of our society'.

Although the report was based on an investigation into the deaths of six adults with a learning disability, evidence from Mencap<sup>22</sup> shows that the same challenges exist in relation to children with a learning disability. In 2008 an independent inquiry by Sir Jonathan Michael<sup>23</sup> found that communication about treatment options with families with disabled children was poor, and

that on occasion these children were denied resuscitation. The inquiry also found major difficulties in the transition to adult health services.

### **Disabled children in hospital**

In February 2009 the Healthcare Commission published a report that looked at the care provided to children in NHS hospitals outside of specialist paediatric settings.<sup>24</sup> This reported the need for 'significant improvement' in areas such as child protection, managing children's pain, life support and skills of surgeons and anaesthetists. Shockingly, it found almost two-thirds of health trusts did not train enough nurses to administer pain relief to children, and that there was 'very limited progress' in training staff to provide life support to children, with ninety-four percent failing to provide basic resuscitation training to surgeons. These are all areas that disproportionately affect disabled children and those with life-limiting conditions.

### **Daisy's story – by her mum**

'When my nine-year-old daughter Daisy, who had a learning disability, died, a doctor at the hospital said to me: 'It's almost like losing a child.' What did he think my beautiful daughter was?

One day, Daisy went into hospital with a tooth infection. Three weeks later she was dead.

During the three weeks Daisy spent in hospital no proactive plan was put into place to save her life. Only her decline was documented. We were never told she was seriously ill. There was never any sense of urgency. When Daisy needed something it would always take so long.

Daisy had not drunk, she had diarrhoea and had been sick, yet they would not turn her drip back on, even though the doctor said she should have it. Daisy went nearly three days without a drink, which is catastrophic for septicaemia. After my protests they turned the drip back on – but she was then given too much fluid, which overloaded her and left her swollen. They told us not to worry.

After Daisy died, we discovered that staff were fully aware that Daisy's life was in danger. They did not try to save her, they just documented her decline. This was not an accident, and it wasn't the case that they did not realise how ill she was. They told us they had 'misjudged her quality of life'. Had she not had a learning disability Daisy would not have been treated this way. It is unacceptable.'

'I had an operation when I was 10. The doctor prescribed me adult painkillers.

The nurses couldn't give them to me. I suffered lots of pain. They should have specialist advice about pain relief for children. When I was ten I was not involved in decisions about operations.

Now I'm older I have been taught more about operations and have more say in the decisions. Making these decisions is hard. I would like an advocate just for me. The health strategy needs to include information and advocacy for young disabled people.'

Adam



### Universal health care – recommendations

- **Training:** PCTs should ensure that all staff working with children receive appropriate training, with particular regard to:
  - **disability equality training and the need to make reasonable adjustments**
  - **the need to communicate appropriately with all children and their parents about their basic needs, using an advocate where necessary**
  - **the need to involve disabled children in decisions about their healthcare and how to ensure that this happens**
  - **the particular vulnerability of disabled children, who are more at risk of abuse than other children**
  - **paediatric training such as children's resuscitation and pain relief.**

# Access to targeted and specialist health services

Many disabled children will need targeted and specialist health services to enable them and their family to lead as ordinary a life as possible. In contrast to universal health services, these are services which usually require an assessment to determine entitlement, and the level of service to be provided. Such services include short breaks, provision of a wheelchair or piece of equipment, incontinence services and therapy services.

In 2004 the Children’s National Service Framework (NSF) standard on disabled children and those with complex health needs set out the following ten-year vision:

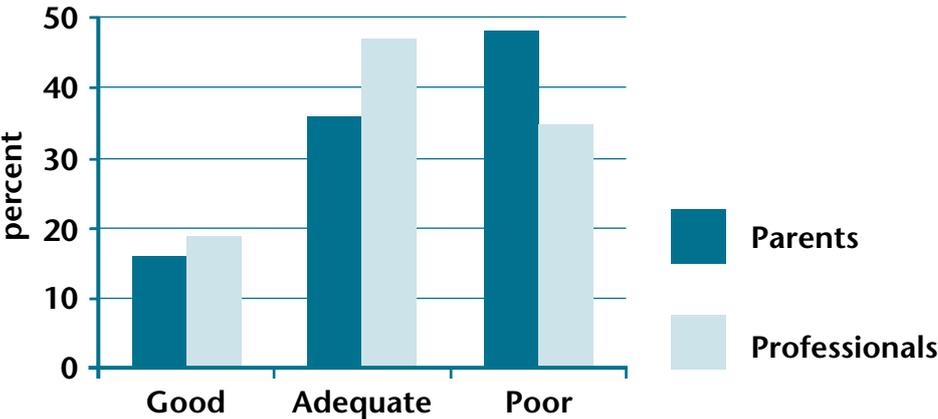
**‘Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.’**

Four years on, the Healthcare Commission’s report ‘The State of Healthcare 2008’ describes the reality for disabled children and their families:

‘Children and young people with complex needs, including children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need...the funding and provision of services for children and young people with learning and/or physical disabilities varies throughout the country.’

There is clearly some way to go to achieve the NSF vision for 2014. The evidence from families and professionals alike is that they experience a postcode lottery in accessing specialist health services. Submissions to the Parliamentary Hearings on Services for Disabled Children held in 2006<sup>25</sup> expressed a high level of dissatisfaction with health services, with almost half of disabled children’s parents (48 percent) and over a third of professionals (35 percent) describing them as poor.

### Levels of satisfaction with health services



## Short breaks

'Part of my son's condition includes severe epilepsy which causes broken sleep. He can wake up five or six times every night and need moving and suctioning. I slept on the floor next to his bed whilst I was begging the PCT for a night nurse. Constant sleep deprivation with no break meant I couldn't function as a mother let alone a carer for my son. After four years I finally got the PCT to agree to provide a night nurse.'

Belinda

**'We are clear... PCTs must find the money to fund short breaks' – Rt Hon Ed Balls MP**

Short breaks are identified as a key priority for delivery and investment in both 'Aiming High for Disabled Children' and 'Healthy lives, brighter futures'. There are now clear expectations, set out in government guidance, on both local authorities and PCTs to deliver additional and better quality short breaks services for disabled children and their families.<sup>26</sup>

In May 2008, Children's Secretary Rt Hon Ed Balls MP stated that 'PCTs have a responsibility, area by area, to find money from their overall budgets to match our spending. Such decisions should be for PCTs, but we are clear, nationally, in our Department and in the Health Department, that PCTs must find the money to fund short breaks'.<sup>27</sup>

Reinforcing this position, short breaks are identified as a priority service to benefit from the £340 million additional investment announced in the child health strategy.

'My daughter has complex health needs and is fed through a tube to her small intestine. At a review meeting of her care the 'professionals' told me that if I wanted short breaks they would send my two other daughters on college courses to learn how to care for her. I was astounded. My other daughters are there to be sisters, to spend time with her, paint her nails and watch Friends with her, not to be her full-time nurses.'

Gilly

In line with the government's expectation, EDCM wants to see all PCTs working in partnership with local authorities to provide short breaks to disabled children with health needs. In particular, PCTs need to ensure short break workers are appropriately trained so that they can offer short breaks to support children with invasive care and complex health needs.

## Community equipment and wheelchairs

'It took me three attempts and two years to get the right wheelchair for my son. It took six months for each wheelchair to arrive so he had already grown out of the first two – what a waste of NHS money! There is still a complete lack of planning for his future needs – which will involve him both growing and needing even more

support as he has a degenerative condition. It is left entirely up to us as parents to anticipate his future needs – and then fight to have them met!’

Belinda

‘NHS wheelchairs are not always very good and some families cannot afford to pay extra. I think it’s good Whizz-Kidz are involved in providing wheelchairs as they have a lot of special knowledge about children and wheelchairs and provide training for disabled children. I went on one of their courses and it was really helpful.’

Adam

AHDC identifies the long-standing challenges facing families who need to access wheelchair and equipment provision. It states:

‘Many children and families currently face long waiting lists for both assessment and provision of equipment and wheelchairs. There is also variation in the overall time taken for social services to provide equipment, and for the NHS to provide wheelchairs. Provision may also focus too heavily on clinical need, and may fail to take into account the impact of independent mobility on social, development and educational attainment, or on families’ preferences (for example, being able to get to school and sit up and learn in class).’<sup>28</sup>

In light of these significant challenges, EDCM welcomes the commitments made in ‘Healthy lives, brighter futures’ in relation to community equipment and wheelchairs:

‘New commissioning models for community equipment for children will be developed, with a series of pilots to begin in 2009-10...[and]... a partnership will be established between Whizz-Kidz and the London Strategic Health Authority in conjunction with PCTs and local authorities to improve commissioning and provision of wheelchairs.’

However we are concerned that around 15,000 young people under 25 with complex needs have an unmet need for specialist mobility equipment<sup>29</sup> and that parents continue to face unclear processes and inconsistent entitlements.

‘My son needs a sleep system – a very basic set of pads he needs in his bed – which the PCT has decided it won’t pay for. We have had to ask a charity to provide it. We know that other PCTs do fund this kind of equipment – it seems to be a complete postcode lottery.’

Suzanne

It is clear that every PCT needs to understand better the level of unmet need in their locality in relation to community equipment, and the additional funds they need to invest to meet that need. In relation to wheelchairs, PCTs need to benchmark their wheelchair provision, to include specific targets against which services for children are monitored.

## Continence services

For many disabled children and their families, continence is a central issue. When assessment, treatment and product supply services are not in place, continence issues can prevent families from living ordinary lives. Even when assessments are available, parents report real problems in securing the supply of the right sort of continence products for their child, with many experiencing a ‘one size fits all’ service.

In 2004 the Children’s NSF<sup>30</sup> recommended ‘an integrated community-based paediatric continence service’ in every area. In 2007 the Department of Health issued the Children’s Continence Exemplar<sup>31</sup> to support the development of child-centred local delivery. Despite these recommendations, integrated paediatric continence services are virtually non-existent.

‘They say it’s a ring back service but they never ring back. You are told to give two weeks for the nappies to arrive and then they don’t. You ring up and they suggest you haven’t placed an order. You argue you have, then they find it and then they tell you the order will be late. There is no understanding that this means you have to go and beg and borrow nappies from where you can. You then complain about the service, but it doesn’t change. You are made to feel it’s your fault. Why isn’t there just a central place you can collect nappies in an emergency? What is it they think we are going to do with them? They make me feel like a criminal.’

Parent

## Therapy services

AHDC recognises the importance of therapy services for disabled children. It states:

‘Therapy services for disabled children are key to improving their outcomes. Speech and language therapists, occupational therapists, and physiotherapists help to enable and promote communication, improve and manage posture, and maximise mobility.’<sup>32</sup>

In particular, speech, language and communication needs (SLCN) are a pan-disability issue. Whilst approximately 7 percent of young children may have SLCN as their main difficulty, other children have SLCN along with or arising from other impairments, for example autism, learning disability or cerebral palsy.

John Bercow MP’s review of SLCN services<sup>33</sup> found that the current system of provision for children with SLCN was ‘characterised by high variability and a lack of equity’. Families described a ‘postcode lottery’, particularly in the context of access to speech and language therapy services.

AHDC cites evidence of long waiting lists and strict eligibility criteria for therapy services as a result of limited budgets and national shortages of trained professionals.<sup>34</sup> Reinforcing this, ‘Healthy lives, brighter futures’ recognises that access to allied health professional services such as physiotherapy and occupational therapy remains variable.<sup>35</sup> However neither strategy sets out a clear plan for addressing these challenges.

**Therapy services are key to improving outcomes**

'My daughter loves using the local hydrotherapy facilities as it's one of the few times she gets to move her body around freely. We are stuck in the middle of an argument between her school and the PCT to get her there because the school says they can only take three children each time logistically but the PCT say they need five children at a time to make it value for money. In the meantime she misses out.'

Gilly

'I went to a mainstream secondary school. I did not get to see a physio or OT regularly. This is because I didn't go to a special school for disabled people. I think health, education and social services need to work more closely together.'

Adam

### **Access to targeted and specialist health services – recommendations**

- **Short breaks:** All PCTs should work with their local authority counterparts to ensure disabled children with health needs access the short breaks they need. This includes joint planning, commissioning and funding of short breaks and addressing workforce implications.
- **Equipment:** Following any pilot work, all PCTs should develop a holistic model of commissioning and providing community equipment to disabled children that meets their social and emotional as well as medical needs. All PCTs should be transparent about how decisions are made in relation to provision of children's community equipment.
- **Wheelchair services:** PCTs should benchmark wheelchair provision, to include specific targets against which services for children are monitored. The Department of Health should require PCTs to report on an ongoing basis their spend on disabled children's wheelchair services.
- **Continence services:** PCTs should develop an integrated and flexible paediatric continence service based on the needs of the local population and in consultation with disabled children and their parents.
- **Therapy services:** PCTs should work with their children's trust partners, including schools, to ensure that access to therapy services is dependent on the individual needs of children, not the needs of the service provider.

## Meeting the needs of children with complex health and/or palliative care needs

Children with complex health needs are a wide and varied group, and include children with life-limiting and life-threatening conditions. Meeting the needs of each child requires an individualised and multi-agency approach. Good data and commissioning of services is also central to planning effectively to meet local need.

### Care-coordination and care planning

'We repeatedly see local agencies 'passing the buck' when it comes to agreeing care for my son. Social services tell us they can't provide night care for him because it is medical care, while health tells us they can't provide it because it is a family support service. Where are the needs of my son in all of this? We haven't seen any evidence of joined-up working, and we are made to feel like we have to beg to get anything done.'

Belinda

'Inter-agency working...multi-agency working... care-coordination... integrated services... multi-disciplinary teams.'<sup>36</sup> These are all concepts the government promotes in relation to working with disabled children, particularly those with complex health needs, and they are concepts EDCM fully supports.

However despite this clear expectation of joined-up working since the introduction of 'Every Child Matters' in 2003, it is clear that many families simply do not see this vision reflected in their own lives.

'My son has an acquired brain injury and has a tracheostomy fitted to enable him to breathe. He has been staying at The Children's Trust, Tadworth whilst he receives rehabilitation, and we want him to come home to live with us and his twin sister. We are fighting the local authority to agree the funding and plans for our home to be adapted and until this is agreed he can't come home. In the meantime the PCT has spent many more times that amount on keeping my son in residential care. The local authority and PCT need to work together to plan for my son's future!'

Suzanne

The Parliamentary Hearings on Services for Disabled Children<sup>37</sup> heard that **key working** was felt to be the most important solution to the challenges of multi-agency working. Parents and professionals recognised the desperate need for greater co-ordination and working across agencies.

Key workers are identified as essential in standard 8 of the Children's National Service Framework, which states they should be 'the main point of contact with the family' and should take responsibility for co-ordinating review meetings and liaising with professionals to ensure all agreed support is delivered.

Despite such clear support in principle for key workers in national policy, many families of children with complex needs remain without one. EDCM wants to see every local area operate a care co-ordination service, adhering to the government-endorsed CCNUK key worker standards.<sup>38</sup> The service should provide holistic support for families with disabled children who access more than one specialist service. The local authority and PCT should jointly plan and identify specific funding to deliver this service.

The child health strategy made a commitment that ‘by 2010, all children with complex health needs will have an **individual care plan**’.

‘Care plans are left to the whim of an individual and I have never had one drawn up. Anyway the problem is that even if you have one you might not agree with what is in it or even get what is in it and there’s no appeal process if that happens.’

Gilly

EDCM supports the principle of care plans, but clear accountability is needed to ensure this commitment truly benefits disabled children and their families. The government needs to state explicitly who is responsible for drawing up this care plan, and require it to be a multi-agency document. Parents must also understand how they can challenge the content of a care plan if they do not agree with it.

EDCM welcomes the government’s intention to create a single national tool for assessing children and young people’s **continuing care needs**. The government’s consultation on a National Framework for Assessing Children and Young People’s Continuing Care<sup>39</sup> recognised that current practice, whereby individual PCTs have developed ad hoc tools to assess eligibility for services and determine levels of provision, has led to unacceptable variations in care between areas. EDCM is also aware that packages of care continue to be segmented between PCT ‘healthcare’ and local authority ‘social care’. Consequently, we expect the final Framework, due for publication at the time of writing, to clarify that PCTs are the lead agency for the arrangement of all care provided to children who have predominantly health needs and for there to be clear duties on PCTs to assess a child who may have continuing care needs. Additionally, once a child is assessed as eligible for continuing care, the PCT and the local authority should be required to state the joint package of care they will put in place to meet the child’s assessed needs.

**Clear accountability is needed for the Department of Health’s commitment to care plans to be meaningful**

### **Planning and commissioning**

AHDC says ‘a clearer picture of the disabled children population and disabled children’s needs at a local level is essential for effective planning, commissioning and provision of services’.<sup>40</sup> However it goes on to say that some areas ‘still do not have a proper understanding of the profile or even the size of their disabled children population’.<sup>41</sup> Whilst EDCM is aware that

some local areas are working to improve their understanding of their disabled children population, practice is not consistent. PCT commissioners need comprehensive and accurate data to plan their services for disabled children, including those with palliative care needs, and should be working with their local authority counterpart (in areas where this is not a joint post) to understand their local population.

**Commissioners must take a holistic and long-term view**

EDCM urges commissioners to recognise the importance of adopting a holistic and long-term view of services for disabled children – a whole system approach. The commissioning guidance<sup>42</sup> issued in support of ‘Healthy lives, brighter futures’ rightly underlines the importance of local children’s trusts providing a ‘robust mechanism’ for partnership and joined up management. Yet the history of fragmented responsibility and attitudinal or cultural differences between agencies still presents obstacles before anything approaching World Class Commissioning<sup>43</sup> of services for disabled children can be achieved.

One of the competencies which the Government has used to describe World Class Commissioning is an expectation that ‘children, young people and families are not just listened to but are fully engaged with the design and delivery of services, in order to secure improved outcomes’. EDCM welcomes this aspiration but is aware it will need more focus before becoming a reality for families of disabled children.

The ‘Healthy lives, brighter futures’ commissioning guidance also addresses the need for regional and national commissioning in some circumstances: ‘In most cases, services and investment will happen at the local level, but in some cases this might happen sub-regionally, regionally or nationally. In general, the more specialised and the lower the volume of the service, the ‘higher’ the level at which it is most appropriately commissioned.’

Present arrangements for national or regional specialised commissioning apply to a defined set of low-incidence health needs. EDCM urges commissioners to consider whether and how these arrangements, particularly for very vulnerable technology-dependent or life-limited children, should be delivered through an integrated pathway of services beyond emergency care. This could be from hospital to rehabilitation in the community after discharge and a package of care at home or support in school. Children with exceptional needs may be small in number, but they can occur in a cluster in a PCT area and it would be helpful then to have an agreed mechanism for spreading the financial burden and avoiding the risk that some children with low-incidence but high-cost needs will lose out for budgetary reasons.

The ‘ACT Care Pathway’ is recognised within ‘Better Care, Better Lives’ as providing a comprehensive care pathway for children with palliative care needs. It is designed to be used within networks as a tool to facilitate commissioning of the full range of services, including hospice services, and to be used with individual children and families according to their needs. EDCM supports the vision of ACT and Children’s Hospices UK for children’s palliative care, that families have real choice relating to place of care, place of death, social opportunities and emotional, psychological and bereavement support.

The challenge for commissioners is to ensure an integrated approach to commissioning to ensure services are available and accessible across the whole care pathway.

### Community Children's Nurses

Community Children's Nurses (CCN's) work with children who require treatment and care for acute and chronic ill health in a home setting.

Numerous government initiatives and studies of service provision have

highlighted the importance of the CCN's role.

The Department of Health are leading an Expert Working Group considering the role and development of CCN services. This links closely to the development of the post-Darzi Transforming Community Services programme as well as workforce modelling and Modernising Nursing Careers, and is expected to identify high impact changes in relation to CCN service development.



'Healthy lives, brighter futures'

describes CCN's as the 'bedrock of local service provision.' 'Better Care: Better Lives' says the same, and adds 'it is essential that these teams are protected and expanded'.

However both strategies fail to make any clear commitments in relation to supporting and developing the CCN workforce, stating only an 'expectation' on commissioners to develop these services.<sup>44</sup> The evidence is that current provision is patchy and inadequate, with a need for greater financial investment within PCTs to deliver the service needed.<sup>45</sup> EDCM wants to see every PCT operate a CCN service, with a core standard of service expectation for each locality.

### Children with complex health and/or palliative care needs – recommendations

- **Key working:** Every children's trust should operate a care-coordination service, adhering to the government-endorsed CCNUK key worker standards. The service should provide holistic support for families with disabled children who access more than one specialist service. The local authority and PCT should jointly plan and identify specific funding to deliver this service.
- **Care plans:** As part of its commitment to individual care plans for every child with complex needs by 2010, the Department of Health should require this to be a multi-agency document with clear processes for parental involvement and feedback.

- **Continuing Care:** The Department of Health should ensure the National Framework for Assessing Children and Young People's Continuing Care introduces a clear duty on PCTs to assess need and PCTs and local authorities should be required to provide a written plan detailing the joint package of care they will put in place to meet the child's assessed needs.
- **Commissioning:** PCT commissioners should establish regional or national commissioning networks to develop and share better integrated and more effective commissioning models for disabled children with the most complex needs.
- **Data:** Every PCT should have an effective system in place to identify their local population of disabled children and children with palliative care needs, assess needs and plan future services. This should be in partnership with the local authority through the Joint Strategic Needs Assessment.
- **Community Children's Nursing:** Every PCT should operate a CCN service, with a core standard of service expectation for each locality.

## System levers and inspection

### Making disabled children a national priority for health

Not only did the NHS Operating Framework 2008-09 identify children as a priority for the NHS for the first time, it specifically identified disabled children as one of four areas requiring local attention for 'recovery action or future improvement'.

The 2009-10 Framework also refers to disabled children, but uses much weaker language, stating 'PCTs will want to review the transparency of their service offer in line with the Child Health Strategy... this may include improving the experience of disabled children and their families...'<sup>46</sup>

Underpinning the NHS Operating Framework is 'Vital Signs', part of the planning framework for PCTs. It is essentially the health equivalent of the National Indicator Set for local authorities. National Indicator 54 on services for disabled children is included in 'Vital Signs', but is included as an optional local priority (Tier 3) rather than a mandatory national priority (Tier 1).

**The Department of Health should take a stricter monitoring role in relation to PCT plans**

Whilst EDCM welcomes the attention given to disabled children at this national level, we are concerned that the messages are relatively weak, and as a Tier 3 Vital Sign PCTs are not required to report at a regional or national level on progress.

We are also concerned there is no clear process for aligning take-up of the indicator and subsequent data collection between the local authority and the PCT.

We do however welcome the letters sent to all PCTs in April 2009 which clarify the proportion of PCT budgets that should be spent on disabled children and the specific actions PCTs are required to take this year in relation

to short breaks, community equipment, wheelchair services and palliative care.<sup>47</sup> This is a step in the right direction. However EDCM would like to see the Department of Health take a stricter monitoring role in relation to PCT plans and expenditure on disabled children on a long-term basis, in line with the government's position on adult end-of-life care. Here the government has committed to looking through individual PCT plans and not to agree these unless PCTs are spending appropriate money.<sup>48</sup> EDCM can see no reason why, having made this exception for adult end-of-life care, the same should not apply for disabled children, a group which includes children with palliative care needs.

### **Making disabled children a local priority for health**

PCTs are guided in their priorities from a number of sources. As set out above, they are expected to be driven by the NHS Operating Framework, whilst responding to the needs of their local population. PCTs set out their priorities in Operational Plans.

In addition, PCTs should be co-operating with the local authority and their partners in children's trusts under the Children Act 2004, and they will have a duty to be part of a children's trust board once the Apprenticeships, Schools, Children and Learning Bill 2009 receives Royal Assent.

The children's trust is central to identifying and agreeing targets in Local Area Agreements (LAAs), the agreement between central and local government that sets out the priorities for improving local services and quality of life. This means the PCT must be driven by the LAA priorities, alongside those in its Operational Plan. Children and Young People's Plans should also set out the improvements to be made in relation to children's health. The local authority should work jointly with the PCT to identify these improvements.<sup>49</sup>

Despite a clear local framework for PCTs to set priorities, EDCM is extremely concerned that there is currently no clearly defined accountability structure within PCTs for disabled children.

**There is no clearly defined accountability structure within PCTs for disabled children**

*'My ten year old son has a rare and life-limiting disability and requires ongoing specialist healthcare. In six years I have never met anyone from the PCT, even at review meetings to discuss his care.'*

*Belinda*

EDCM wants to see a named lead in every PCT at a strategic level responsible for services for disabled children and children with complex health and palliative care needs. In areas where an integrated service between the local authority and PCT is already established, this individual should be jointly funded by the local authority and PCT.

## Making disabled children a priority for health inspections

Effective inspection of health services for disabled children has the potential to drive improvement in services locally. Responsibility for the inspection and regulation of adult and children's health services and adult social care passed to the Care Quality Commission (CQC) in April 2009.

EDCM welcomes the announcement that the CQC will carry out a special review of health services for disabled children. EDCM urges the CQC to consider how it will work with the children's social care inspectorate Ofsted, to examine how children's health and social care services are working together to improve outcomes for disabled children.

### System levers and inspection – recommendations

- **National priority:** The Department of Health should inform PCTs that their annual Operating Plans will not be agreed unless they demonstrate that their spend on disabled children's services and children's palliative care services reflects national policy expectations.
- **Local priority – leadership:** Every PCT should have a named lead at a strategic level responsible for services for disabled children, including children with complex health needs and children with palliative care needs, by December 2009.
- **Inspection:** The Care Quality Commission and Ofsted should ensure that their inspections of disabled children's services take a holistic approach to the experiences of disabled children and their families and do not emphasise a divide between 'health', 'education' and 'social care' services.

## Transition from child to adult health services

The challenges faced by disabled young people moving from child to adult services, and the failure of services to address these challenges effectively, have been well documented, including in guidance from the Department of Health.<sup>50</sup>

Leaving behind secure relationships with health professionals in paediatric services that have cared for the child and supported the family for the majority of the child's life is daunting. Often families are left with no clear plan regarding transfer to adult health services and are effectively left to start over again to tell their child's story. With more disabled young people surviving into adulthood, there can be limited expertise within adult health services regarding those conditions that previously would have caused a child to die at an earlier age.

EDCM welcomes the guides that aim to support health practitioners address the identified risks that disabled young people face during the transition process. However, it is clear through initial findings from the

Transition Support Programme<sup>51</sup> that many local areas are struggling to fully implement the guidance or recognise its importance in ensuring that disabled young people have positive health outcomes. This means the negative outcomes that disabled young people and their families experience when poor transition arrangements are in place span all of the key challenge areas highlighted in this briefing.

Specific focus must be given to improving transition processes for disabled young people if any improvements in outcomes that are made in children's health services are to be maintained as young people move into adulthood.

### Transition – recommendations

- **Commissioning:** PCT commissioners for child and adult health services should work together through joined-up needs assessments to identify local trends and plan for future needs of disabled young people.
- **Transition planning:** PCT practitioners should have input into every case of multi-agency transition planning (year 9 education review) where disabled young people have a complex health need.

### A note on health and well-being

The briefing sets out issues relating to health services specifically, rather than services more generally which can have an impact on the health and well-being of disabled children such as play and leisure services. However EDCM is keen to emphasise the importance of these services, which feature throughout the recent child health strategy, and require a joint approach by a range of services including social care and education, in order to address the holistic needs of disabled children. For example, 'Healthy lives, brighter futures' states: 'The PE and Sport Strategy for Young People will focus on a number of areas, including 'providing more support for... children with disabilities.'

'I wasn't involved in PE much in mainstream school. This is because I couldn't do a lot of the sports. This wasn't good as I wasn't doing anything active. The school should have made sure there were things I could do. Now I've joined a Boccia club. I compete in national events. I have also been involved in fundraising for the club.'

Adam

### Health and well-being – recommendation

- **Inclusion:** The Department of Health should state explicitly how it will ensure local areas will be supported to deliver its commitment to 'provide more support for children with disabilities' through its PE and Sport Strategy, alongside other commitments to the inclusion of disabled children in 'Healthy lives, brighter futures'.

## Conclusion and summary of recommendations

It is clear that despite the recent focus on the health needs of disabled children at a national level, there is still a long way to go before central government policy results in clear improvement in local delivery of health services and therefore better health outcomes for disabled children and their families.

The devolved nature of health policy and funding makes it even more important that PCTs rise to the challenge of meeting the needs of their local population of disabled children.

However, the government has now set out clear expectations regarding PCT funding and practice in relation to disabled children, and should therefore take steps to ensure PCTs are meeting those expectations.

But improving the lives of disabled children and their families is not just about money. There are many examples of families' experiences where a change in attitude, improvement in training, joint planning and partnership working can lead to more positive outcomes. However this can only take place if every PCT establishes a strong leadership role to drive the government's vision for disabled children forward.

Local authorities are already over a year into delivering the Aiming High for Disabled Children 'transformation programme' for their disabled children's services – PCTs need to quickly follow suit and work in partnership with local authorities if disabled children are to receive holistic, child-centred services that will support them to fulfil their potential.

### Summary of recommendations

#### **Accountability and transparency of health funding – recommendations**

- **Transparency:** Every PCT should publish information on the additional funding they have allocated locally for each financial year (2008-2011) to disabled children's services, separately identifying short breaks, children's community equipment, children's wheelchairs and children's palliative care.
- **Scrutiny:** The Department of Health should scrutinise PCT statements in September 2009 and challenge PCTs who are not performing in line with national policy and investment expectations. The Department of Health should also make those statements public.

#### **Universal health care – recommendations**

- **Training:** PCTs should ensure that all staff working with children receive appropriate training, with particular regard to:
  - disability equality training and the need to make reasonable adjustments
  - the need to communicate appropriately with all children and their parents about their basic needs, using an advocate where necessary
  - the need to involve disabled children in decisions about their healthcare and how to ensure that this happens
  - the particular vulnerability of disabled children, who are more at risk of abuse than other children
  - paediatric training such as children's resuscitation and pain relief.

## Access to targeted and specialist health services – recommendations

- **Short breaks:** All PCTs should work with their local authority counterparts to ensure disabled children with health needs access the short breaks they need. This includes joint planning, commissioning and funding of short breaks and addressing workforce implications.
- **Equipment:** Following any pilot work, all PCTs should develop a holistic model of commissioning and providing community equipment to disabled children that meets their social and emotional as well as medical needs. All PCTs should be transparent about how decisions are made in relation to provision of children's community equipment.
- **Wheelchair services:** PCTs should benchmark wheelchair provision, to include specific targets against which services for children are monitored. The Department of Health should require PCTs to report on an ongoing basis their spend on disabled children's wheelchair services.
- **Continence services:** PCTs should develop an integrated and flexible paediatric continence service based on the needs of the local population and in consultation with disabled children and their parents.
- **Therapy services:** PCTs should work with their children's trust partners, including schools, to ensure that access to therapy services is dependent on the individual needs of children, not the needs of the service provider.

## Children with complex health and/or palliative care needs – recommendations

- **Key working:** Every children's trust should operate a care co-ordination service, adhering to the government-endorsed CCNUK key worker standards. The service should provide holistic support for families with disabled children who access more than one specialist service. The local authority and PCT should jointly plan and identify specific funding to deliver this service.
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- **Community Children's Nursing:** Every PCT should operate a CCN service, with a core standard of service expectation for each locality.

## System levers and inspection – recommendations

- **National priority:** The Department of Health should inform PCTs that their annual Operating Plans will not be agreed unless they demonstrate that their spend on disabled children's services and children's palliative care services reflects national policy expectations.
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- **Inspection:** The Care Quality Commission and Ofsted should ensure that their inspections of disabled children's services take a holistic approach to the experiences of disabled children and their families and do not emphasise a divide between 'health', 'education' and 'social care' services.

## Transition – recommendations

- **Commissioning:** PCT commissioners for child and adult health services should work together through joined-up needs assessments to identify local trends and plan for future needs of disabled young people.
- **Transition planning:** PCT practitioners should have input into every case of multi-agency transition planning (year 9 education review) where disabled young people have a complex health need.

## Health and well-being – recommendation

- **Inclusion:** The Department of Health should state explicitly how it will ensure local areas will be supported to deliver its commitment to 'provide more support for children with disabilities' through its PE and Sport Strategy, alongside other commitments to the inclusion of disabled children in 'Healthy lives, brighter futures'.

**EDCM and its partners will be lobbying government Ministers and local health and children's services decision-makers to take action against these recommendations.**



- 1 Department of Health (2008) High Quality Care for All. NHS Next Stage Review Final Report
- 2 Department for Education and Skills and Department of Health (2009) Healthy lives, brighter futures. The strategy for children and young people's health
- 3 Disability Rights Commission (2006) Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems
- 4 Healthcare Commission (2008) State of Healthcare 2008
- 5 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families
- 6 Prime Minister's Strategy Unit (2005) Improving the Life Chances of Disabled People
- 7 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families
- 8 Jeanne Carlin (2005) Including Me. Managing complex health needs in schools and early years settings
- 9 Department of Health (2007) Palliative Care Statistics for Children and Young Adults
- 10 Estimate by Whizz-Kidz
- 11 Right to health under Article 25 of the UN Convention on the Rights of Persons with Disabilities and child's right to health and health services under Article 24 of the UN Convention on the Rights of the Child.
- 12 'PCTs will also want to begin preparing for action on those issues that will need addressing to secure future improvements in services.... Specifically this includes:... disabled children: identifying actions and setting local targets on improving the experience of, and ranges of services for, children with disabilities and complex health needs and their families. This includes significantly increasing the range of short breaks, improving the quality and experience of palliative care services, improving access to therapies and supporting effective transition to adult services.' (NHS Operating Framework for 2008-09, p.22). 'PCTs will want to review the transparency of their service offer in line with the Child Health Strategy, to be published shortly, and local priorities. These may include:... improving the experience of services for children with a disability and their families, including palliative care' (NHS Operating Framework for 2009-10, p. 17).
- 13 Department of Health (2008) National Planning Guidance and "vital signs"
- 14 Department of Health (2008) Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions
- 15 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families
- 16 Department for Education and Skills and Department of Health (2004) National Service Framework for Children, Young People and Maternity Services
- 17 UN Committee on the Rights of the Child (2008) Concluding Observations
- 18 In December 2007 Ministers wrote to local authorities and PCTs stating there was additional funding for all PCTs in their baselines to deliver the AHDC programme and improve children's palliative care. However the level of funding was not specified. In February 2009 'Healthy lives, brighter futures' stated that an additional £340 million had been given to Primary Care Trusts for disabled children from 2008 – 2011, including £30 million for children's palliative care services. In April 2009 two joint letters were sent to PCTs from the Department of Health and the Department for Children, Schools and Families. These clarified further that 1.23 percent of the £27,596m additional resources the Department of Health is making to PCTs from 2008-2011 was for disabled children's services. The priority areas that should benefit from this expenditure are short breaks, community equipment, wheelchair services and palliative care. The letters also required SHAs and PCTs to report on their plans and performance in these areas in September 2009.
- 19 National Autistic Society (2003) GPs on Autism
- 20 Action for Children (upcoming release) The PCT Perspective: Delivering the Aiming High for Disabled Children Programme
- 21 Health and Local Government Ombudsman (2009) Six lives: the provision of public services to people with learning disabilities
- 22 Mencap (2007) Death by Indifference
- 23 Sir Jonathan Michael (2008) Healthcare for All
- 24 Healthcare Commission (2009) Improving services for children in hospital
- 25 Every Disabled Child Matters (2006) Parliamentary Hearings on Services for Disabled Children
- 26 Department for Children, Schools and Families and Department of Health (2008) Aiming High for Disabled Children: Short Breaks Implementation Guidance
- 27 Secretary of State for Children, Schools and Families Rt Hon Ed Balls MP, 19 May 2008, oral answer to House of Commons question
- 28 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families – Para 4.40
- 29 Whizz-Kidz estimate
- 30 Department for Education and Skills and Department of Health (2004) National Service

- Framework for Children, Young People and Maternity Services
- 31 Department of Health (2007) Children's Continence Exemplar
- 32 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families – Para 4.13
- 33 John Bercow (2008) The Bercow Report. A Review of Services for Children and Young People (0–19) with Speech, Language and Communication Needs
- 34 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families – Para 4.51
- 35 Department for Children Schools and Families and Department of Health (2009) Healthy lives, brighter futures, the strategy for children and young people's health – Para 6.67
- 36 All from Department for Education and Skills and Department of Health (2004) National Service Framework for Children, Young People and Maternity Services
- 37 Every Disabled Child Matters (2006) Parliamentary Hearings on Services for Disabled Children
- 38 Care Co-ordination Network UK standards are at [www.ccnuk.org.uk](http://www.ccnuk.org.uk)
- 39 Department for Children, Schools and Families and Department of Health (2008) Consultation on a National Framework for Assessing Children and Young People's Continuing Care
- 40 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families – Para 3.9
- 41 HM Treasury and Department for Education and Skills (2007) Aiming High for Disabled Children: Better Support for Families – Para 3.10
- 42 Department for Children Schools and Families and Department of Health (2009) Securing better health for children and young people through world class commissioning
- 43 Department of Health (2007) World Class Commissioning
- 44 Department for Children Schools and Families and Department of Health (2009) Healthy lives, brighter futures, the strategy for children and young people's health – Para 6.38
- 45 Royal College of Nursing and WellChild (2009) Better at Home campaign
- 46 Department of Health (2008) The Operating Framework for the NHS in England 2009/10
- 47 The letters can be downloaded from [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_097376](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_097376) The letter from Children's Secretary Rt Hon Ed Balls MP and Health Secretary Rt Hon Alan Johnson MP clarifies for PCTs that 1.23 percent of the £27,596m additional resources the Department of Health is making to PCTs from 2008-2011 is for disabled children's services. It emphasises the importance of local partnership working to embed national priorities into local delivery plans. The letter from Christine Beasley, Chief Nursing Officer, and David Flory, Director General NHS Finance sets out the priority areas that should benefit from this expenditure and states that PCTs will be asked to prepare a commentary on their disabled children's services to accompany the publication of 2008-09 performance data in September 2009.
- 48 NHS Chief Executive David Nicholson told a Public Accounts Committee inquiry into end-of-life care on 17 December 2008: "We are making a slight exception for end of life care...perhaps you need some special arrangements, and we have arranged it so that, whilst the money is not ring-fenced, PCTs will have to account for the amount of money that they have got for the end of life care, and we will monitor that over the next two or three years to make sure that they are spending it in the way that we have described as part of the End of Life Care Strategy....We will look through each individual [PCT] plan to see... that they are spending appropriate amounts of money, and we will not agree their plans unless they are".
- 49 Regulation 4 of Children and Young People's Plan Regulations 2005:  
4(1)Each plan shall set out the improvements which the authority intend to make during the plan period to the well-being of children and relevant young persons so far as relating to  
(a) physical and mental health and emotional well being
- 50 Department of Health (2006) Transition: getting it right for young people and Department of Health (2008) Transition: moving on well
- 51 The Transition Support Programme aims to raise the standards of transition in all local areas. More information at [www.transitionsupportprogramme.org.uk](http://www.transitionsupportprogramme.org.uk)

**Every Disabled Child Matters** (EDCM) is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium.

Find out more and sign up to support the campaign at [www.edcm.org.uk](http://www.edcm.org.uk)

This briefing can be downloaded from our website  
[www.edcm.org.uk/health](http://www.edcm.org.uk/health)

For hard copies or for further information, contact the campaign team:

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PCTs in England can sign up to the EDCM PCT Charter. Find out more at  
[www.edcm.org.uk/pctcharter](http://www.edcm.org.uk/pctcharter)

This briefing paper relates to England only. EDCM has sister campaigns in each of the UK nations:

### **Wales**

Disabled Children Matter Wales  
[www.dcmw.org.uk](http://www.dcmw.org.uk)

### **Scotland**

For Scotland's Disabled Children  
[www.capability-scotland.org.uk/forscotlandsdisabledchildren.aspx](http://www.capability-scotland.org.uk/forscotlandsdisabledchildren.aspx)

### **Northern Ireland**

Children with Disabilities Strategic Alliance  
[www.ci-ni.org/working\\_in\\_partnership.aspx?dataid=330491](http://www.ci-ni.org/working_in_partnership.aspx?dataid=330491)

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