



# Aiming high for disabled children: delivering improved health services



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# Executive summary

There are around half a million disabled children in England, which represents up to 18 per cent of the child population, with the numbers rising. Disabled children also use NHS services significantly more than other children so it is important that PCTs consider their needs when commissioning services.

Providing effective health services for disabled children will improve outcomes for disabled children and their families and ensure the child receives the best quality of care. Moreover, as the NHS spends a much higher proportion of its budget ensuring that they meet the needs of disabled children, improvements in the delivery of services for disabled children will provide better value for money.

During the past two years, the Government has paid special interest to improving health services for disabled children and their carers. Children are one of the key priorities on the NHS Operating Frameworks for 2008-09 and 2009-10. Also, *Healthy lives, brighter futures*, the first Child Health Strategy, was published earlier this year.

There is a total of £340 million in NHS allocations over the three years from 2008/09 to 2010/11 to improve services for disabled children, including £30 million for children's palliative care. The key areas for improvement are: short breaks, community equipment, wheelchairs and children's palliative care. PCTs will have to produce a statement in the autumn explaining the improvements they have made in these areas. The appendix in this report (page 16) provides a guide to what PCTs should cover in their statement.

Some PCTs are finding it challenging to develop new ways of working. This report highlights examples of services for disabled children that meet users' needs, respond to the government agenda and are effective from both a quality and a cost point of view.

# Background

Ensuring children and young people grow up healthy is a priority in any society. The Government has indicated a growing interest in ensuring the needs of children in the UK are taken into account when designing services, including healthcare services.

As set out in the recent Child Health Strategy *Healthy lives, brighter futures*, when commissioning or providing services for children, PCTs are expected to think about those with a range of disabilities. PCTs will have to issue a statement in the autumn explaining what they have done to meet the requirements of *Aiming High for Disabled Children* and the children's palliative care strategy *Better Care, Better Lives*, through improving access to short breaks as well as provision of community equipment and wheelchairs, palliative care and end of life care.

There are around half a million disabled children in England<sup>1</sup>. This figure represents about up to 18 per cent of the child population<sup>2</sup>. The NHS spends a much higher proportion of its budget ensuring that disabled children have their needs met than providing services for their non-disabled counterparts. Looking at expenditure on disability

services as a proportion of spend on targeted services, disability spend accounted for 18 per cent. Moreover, as advances in medicine will increase the range of treatments and care services available for disabled children, PCTs expenditure in this area will increase. According to the Department of Health (DH), expenditure on services for children with a disability already rose by 100 per cent from 2005/06 to 2006/07.

Providing effective health services for disabled children will improve outcomes for disabled children and their families, ensure the child receives the best quality of care and provide better value for money. This report examines best practice around the country. It draws on examples of services for disabled children that meet users' needs, respond to the government agenda and are effective from both a quality and a cost point of view.

*'The NHS spends a much higher proportion of its budget ensuring that disabled children have their needs met than providing services for their non-disabled counterparts.'*

# The context

Recent national policy developments have prioritised disabled children. *Healthy lives, brighter futures*, the Child Health Strategy, was published earlier this year. It is the Government's latest commitment to improving the health of the younger population in general, and disabled children are a key feature. There is a total of £340 million in NHS allocations over the three years from 2008/09 to 2010/11<sup>3</sup> which should be destined to improving services for disabled children, including £30 million for children's palliative care. This budget represents 1.23 per cent of the additional resources that the DH is making available to PCTs for the period 2008/09 to 2010/11.

A letter from the DH and the Department for Children, Schools and Families (DCSF) about the child health strategy and disabled children sent to all PCT chief executives on 2 April<sup>4</sup> stated that the key outcomes for the priority areas for PCTs are listed in the box below.

A number of PCTs have been able to develop new ways of working with this funding. However, others are finding it a challenge. In correspondence with

the Every Disabled Child Matters 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 from year to year
- commissioning processes for some services (for example 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<sup>5</sup>.

The Child Health Strategy builds on existing government policy and initiatives such as

## Key outcomes of priority areas for PCTs

**Short breaks:** ensure that disabled children with complex healthcare needs and their families can enjoy the same opportunities for short breaks as other children.

**Community equipment:** the NHS to work with partners to ensure there is timely and comprehensive assessment of the complete needs of the disabled child, taking account of clinical, social and education needs, and the needs of the family and carers; and to improve the timely provision of equipment.

**Wheelchairs:** to improve access to powered wheelchairs for children who need them, and reduce waiting times for assessment and provision; PCTs to set themselves goals for making this offer in all new cases and as they replace equipment for existing users.

**Children's palliative care:** to develop services to meet the goals in *Better Care, Better Lives* – in particular to develop children's community nursing, capable of providing an all round care package, including end of life care, 24 hours a day, seven days a week, in the location the child and family prefer; as as building capacity in children's palliative care networks.

*Aiming High for Disabled Children*<sup>6</sup> and Standard 8 of the National Service Framework for Children<sup>7</sup>. National Indicator 54 has been introduced as a result of *Aiming High* and forms part of the local authority national indicator set (NI54) and is also one of the NHS 'vital signs' indicators (VSC33). It is based on parents' experience of services and the 'core offer' that 'sets out in one place a national statement of expectations for how disabled children and their families will be informed and involved as their needs are assessed and the necessary services are delivered'. The guidance underpinning the core offer makes clear that it relates to both local authorities and PCTs<sup>8</sup>.

The NHS Operating Frameworks mentioned disabled children both in 2008-09 and in 2009-10. More specifically, *Better Care, Better Lives* sets out clear expectations for PCTs to improve the service for children and young people with a life-threatening and/or a life-limiting condition.

NHS organisations have started to adapt their services to respond to the needs of their growing young disabled population and the Government's expectations. However, as the Healthcare Commission put it, 'some were not receiving the range of experiences and services that young people need if they are to live a fulfilled adult life and feel part of the wider community'<sup>9</sup>. Insufficient data about which services are more effective and a lack of clarity about PCTs' funding and responsibilities mean that the service is patchy.

Up to now, PCTs have faced a number of system challenges in relation to meeting the needs of disabled children:

- Child Health Mapping has improved the data about child health services but this is still very poor
- a lack of clarity from the DH on where disabled children fit in the context of competing NHS priorities

- complexities on the budget allocation, which have been clarified after many PCTs had allocated their budget for 2008/09 and 2009/10
- different systems and accountability for partners - this is particularly important for PCTs and local authorities because of their need to cooperate.

The complexity of disabled children's needs means that their needs are only met when health and social care work together effectively. Examples of this include the joint planning and commissioning strategies and joint appointments, explored further in the case studies within this report.

## Provision of equipment and wheelchairs

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Disabled children are often not provided with adequate equipment in a timely fashion. The Audit Commission found repeated examples of unacceptable waits for equipment which, when it was made available, was often unresponsive to need<sup>10</sup>. The review also found that waiting for equipment was a universal experience resulting in frustration and waste and with lasting social, physical and emotional consequences.

Equipment is a very important part of many disabled children's lives. Having access to adequate equipment can make the difference between meeting only the child's medical needs or also their wider social, emotional and daily living needs. Unclear budgets and responsibilities can make it difficult for children to access the equipment that enables them to be part of the community. Working with third sector organisations can bring opportunities for commissioning and delivering new service models. An example can be seen in the provision of wheelchairs for disabled children (overleaf).

## Case study: Joint working with the third sector

Tower Hamlets PCT and the charity Whizz-Kidz, which is an expert on paediatric mobility services, pooled resources and expertise to improve the way they provided wheelchairs to local disabled children.

Having worked jointly before, the PCT provided a grant to Whizz-Kidz in April 2008 to run the paediatric wheelchair service on its behalf. Whizz-Kidz assesses and prescribes to all children and young people aged up to 25 years. There is very close liaison with the wheelchair service during the transition to adulthood and joint assessments are often carried out in this period. In the first full nine months of operation, over 130 children were assessed and provided with equipment which met their needs, including 13 indoor/outdoor powered chairs.

The partnership has proven to be very effective:

1. A recent user survey indicated a satisfaction rate of 100 per cent for equipment and 86.67 per cent for services.
2. The education service has fed back to the PCT that they are very pleased with the increased independence that the service has given to local disabled children.
3. The waiting list has been cleared.
4. Waiting times for provision have reduced to below 18 weeks in most cases.
5. There has been a significant increase in the number of children who can access the service.
6. A dedicated development officer has joined the team to ensure that BME children, who had previously been identified as a hard to reach group in this area, receive equal access to wheelchairs.

Whizz-Kidz and Tower Hamlets PCT have commissioned an independent evaluation. It will be carried out at the end of 2009 and both expect to find significant cost savings. Both organisations have found that the partnership has improved the quality of their services significantly. They believe that the key to success is seeing the partnership as an opportunity to transform services, not simply a way of shifting the problem.

## Short breaks

Short breaks are identified as a key priority for delivery and investment in both *Aiming High for Disabled Children and Healthy lives, brighter futures*. Short breaks are also a priority service to benefit from the £340 million additional funding announced in the Child Health Strategy. There are now clear expectations on PCTs to delivery good

quality short breaks for disabled children and their families. The letter from the DH and DCSF about the Child Health Strategy and disabled children sent to all PCT chief executives in April stated that, in relation to short breaks, PCTs should 'ensure that disabled children with complex health needs and their families can enjoy the same opportunities for short breaks as other disabled children'<sup>11</sup>.

A report from PricewaterhouseCoopers<sup>12</sup> in 2007 found that in some instances short breaks can reduce long-term costs of intervention. A number of research studies like the ones carried out by Beresford in 1994<sup>13</sup> or by Chan and Sigafos in 2001 also suggest that short break services may lead to significant savings to residential care budgets as they enable parents to continue caring for their disabled child at home and reduce family stress. Importantly, they also provide disabled children with enjoyable experiences away from their primary carers, thereby contributing to their personal and social development and reducing social isolation.

### Case study: Improving skills

Early assessment of the Aiming High for Disabled Children programme in both NHS Coventry and NHS Warwickshire identified that staff would need to develop their skills to improve the service provided to children with complex needs in short break settings. In order to ensure that staff in short break settings could deliver the nursing care that some children need, both PCTs recruited a clinical educator in each of their Community Children's nursing teams. The post-holder delivers training to parents, foster carers, NHS and local authority staff, family link workers and voluntary sector workers to enable children to access a wide variety of short break provisions. The evaluation of the competency system has been that it is now widely accepted and gives organisations the confidence to allow their staff to undertake the complex nursing care that some children require and has therefore increased their access to short breaks.

*'It is important for health organisations to identify the needs of disabled young people to ensure they develop a strategic plan that responds to their needs as they develop into adults.'*

## Transition from childhood to adulthood

Transition across traditional age boundaries is an increasing issue for health services. Developing and providing services that support disabled young people in their transition to adulthood can be a challenge for commissioners of both children's and adult services. Service delivery and entitlements differ greatly from childhood to adulthood. Also, disabled young people with rare or chronic degenerative conditions are living longer and surviving into adulthood more frequently. Since services for these conditions had been traditionally developed within children's services, adult services frequently have a limited expertise regarding these conditions. It is therefore important for health organisations to identify the needs of disabled young people to ensure they develop a strategic plan that responds to their needs as they develop into adults.

The DH has produced a series of guidance documents to address the challenges faced by disabled young people in transition<sup>14</sup>. However, initial findings of the National Transition Support Programme suggest that some areas are struggling to implement the guidance.

## Case study: Transitional services

- Young people (10-18-year-olds) with rheumatic conditions represented approximately a third of the workload of the rheumatology services in Birmingham Children's Hospital. An evidence-based transitional care programme was developed, including a new team<sup>15</sup>.

This new team has allowed the rheumatology team at Birmingham Children's Hospital to provide a more targeted and personalised service for young people with chronic rheumatic disease like juvenile idiopathic arthritis. There is now in place:

- clinical leadership for adolescent rheumatology – shared by a consultant – and occupational therapy
- one part-time adolescent transition care coordinator (charity funded)
- weekly multidisciplinary adolescent clinics and adolescent team meetings
- peer support activities, including a residential summer camp
- a series of informational resources including a dedicated website ([www.dreamteam-uk.org](http://www.dreamteam-uk.org)), farewell cards for young people when they transfer to adult care and better communication with young people, for example, a written departmental transition policy
- copy clinic letters for all young people and a patient-held transfer summary
- an individualised transition plan which starts at age 11 but covers early, mid and late adolescent plans and another plan for their parents
- quarterly young adult clinics for 16- to 25-year-olds in two adult hospitals.

Evaluation at 12 months showed significant improvements in patient and parent satisfaction, disease knowledge, vocational readiness and health-related quality of life<sup>16</sup>. Subsequent evaluation has shown improved management skills among health issues<sup>17</sup> and increased self-management skills among young people<sup>18,19</sup>. The services offered follow the NSF standards and DH guidance for transitional care and are on their way to meet the You're Welcome quality criteria for young person-friendly services. In 2005, they were already awarded the BUPA Clinical Excellence Award.

## Complex health needs

Some children with the most complex needs find themselves living in hospital for many months unnecessarily. This can have worsening effects on the well-being of the child and their carers. A paediatric intensive-care or high-dependency unit

ward is not the most appropriate place for a child to stay in for long periods of time. Moreover, their long stay places extra demand on health budgets. It is estimated that hospital care for a child with complex medical needs costs around £1,500 to £2,500 per night, excluding any additional specialist medical or therapy costs<sup>20</sup>.

Specialised services based in the community can ensure a smooth transition from hospital to home, while making the experience less stressful for the child and their parents. Evidence also suggests that this can be more cost efficient. An example from The Children's Trust, Tadworth, shows that a transitional programme typically lasting from nine to 12 months, costs around £1,300 per night, including all therapy, education and leisure activities.

PCTs have been directed to consider expanding their provision of Children's Community Nurses (CCN). The DH is currently leading an expert working group to look at the role and development of CCN services. These services have been praised in several government documents, including *Healthy lives, brighter futures* and *Better Care, Better Lives*. There are also close links with the post-Darzi Transforming Community Services programme. However, there is evidence that current provision of dedicated teams is patchy.

### Case study: The Children's Trust, Tadworth

The Children's Trust, Tadworth's transitional care service, is a bridge between specialist hospital care and a home for children who are dependent on long-term artificial ventilation or complex tracheotomies. It is the first transitional care unit in the UK to be established outside a hospital. The service was established in 2006 in response to a number of enquiries from hospital-based clinicians who were looking for an alternative to long-term hospital care for technology-dependent children.

Children are referred to the trust by their hospital clinical team and their placement is funded by their PCT. Once admitted, they benefit from the daily input of a multidisciplinary team that includes doctors, specialist nurses, therapists and teachers, along with a full programme of play and leisure activities. This differs from most hospital transitional units, which have limited education, therapy and leisure provision.

Therapies focus on reducing the child's reliance on technology and developing their independence, while regular school work and leisure activities prepare them for discharge by providing them with the opportunity to refamiliarise themselves with community settings and generalise the skills they have developed.

Accommodation is provided on site for parents, who are prepared for the return home with training and support in understanding their child's condition, managing their equipment and useful therapy techniques. This training is also offered to the child's community nursing team ahead of discharge.

This service ensures that children receive more appropriate and tailored care. Children who had been living in hospital have been given a pathway home and a better quality of life during the transition process. Each child's progress has been holistic: they have made medical and physical progress as well as reaching their social and behavioural goals – all essential to their rehabilitation into life back at home.

## Training

Health staff who work with disabled children need to have the right skills. Several reports, including a study carried out by the Healthcare Commission<sup>21</sup>, have highlighted that NHS staff are not receiving sufficient training in the areas such as child protection, managing children's pain, life support, relief administration or anaesthetics. Other important areas for training are disability awareness, including how to communicate with children who may communicate in ways other than speech. The Child Health Strategy calls for better training for health staff. It also asks

commissioners to consider the expansion of their trained paediatric workforce, including children's nurses, as part of their workforce planning strategy.

Effective services can only be delivered if staff delivering care have the necessary skills. This needs to be supported by an effective training programme able to respond and adapt to the local needs. The best way to deliver appropriate training is by organisations working in partnerships. NHS organisations, for example, can ensure that their local partners receive any healthcare-related training that may help them in their job.

### Case study: The Diana Service Training Programme

The Diana Training Programme, in Leicester, was established in its current form in 2006 in response to the growing demand on the Diana Service staff to provide education and training to staff working in all sectors who were caring for a child with an additional health need. This included providing training to health professionals.

The Diana Service was committed to providing high-quality, effective and safe training to all carers from any agency caring for children requiring a clinical intervention, thus enabling children to access safe, high-quality care.

Between 2006 and April 2009, 1,364 staff members from all sectors including health, education, social care and the voluntary sector have accessed the training. Staff from all agencies are trained together on the study days.

The service provides a range of theory-based training on a variety of topics, including epilepsy awareness and administration of emergency medication; enteral feeding; respiratory care; tracheotomy care and care of child requiring long-term mechanical ventilation. An assessment framework tool is used to undertake assessments, where required. Once deemed competent, all staff are offered continued advice and support. An exciting new development for the service is the move to e-learning, which should go live by the end of 2009 or early 2010.

The training programme has improved the quality of care delivered; particularly, the safe delivery of care to children and young people with additional needs. Staff are trained and supported to be able to provide care to children who would otherwise not be able to access a wide variety of settings.

Investment in this area has also led to efficiency savings which are important for providers. Staff employed in support roles are able to safely carry out the care required without the need for trained nurses to be present. The training provided enables staff from a wide variety of agencies to provide short breaks for children, young people and families. Evidence suggests that this may contribute to the prevention of hospitalisation and family breakdown with related cost savings.

## Palliative care

There are an estimated 23,500 children aged up to 19 years of age in the UK with a life-limiting or life-threatening condition requiring access to palliative care<sup>22</sup>. This trend is on the increase, placing more demands on health services.

Through the Child Health Strategy *Healthy lives, brighter futures*, PCTs have been allocated £30 million from 2008-11 to implement the recommendations of *Better Care, Better Lives*, the children's palliative care strategy. This includes ensuring services for children with palliative care needs and complex needs are commissioned and coordinated effectively.

### Case study: Richard House Children's Hospice

Richard House Children's Hospice in East London was created to address a large need for short breaks and end of life care for children and young people aged up to 19 years living with a life-threatening, life-limiting or a complex healthcare condition within the Greater London boroughs.

Richard House is part of a strong network. The organisation is now leading on a series of innovative partnerships with commissioners, statutory and voluntary providers. These include:

- a partnership with Newham PCT that has led to the funding of the Diana Team, which includes a home respite service
- a partnership with Newham Hospital NHS Trust Health Advocacy Service to provide cultural, language interpreting and advocacy services within the hospice and surrounding community
- a partnership with the Royal London Hospital and the North East London Specialised Commissioners to fund support to children with long-term ventilation (LTV) needs, to establish a step down service for children on LTV from hospital to home
- a service-level agreement with Great Ormond Street Hospital Palliative Care Team (including consultants in children's palliative care) to provide end of life care and specialist advice to children and young people accessing Richard House
- a partnership, funded by a corporate organisation and subcontracted to the Rainbow Trust to provide a range of support to children and families in the own home
- a partnership with Tower Hamlets PCT to provide physiotherapy and occupational therapy support to children and families
- a service-level agreement with Newham Hospital NHS Trust for multi-faith chaplaincy services.

Partnership working is integral to everything Richard House does. While they view themselves as a 'children's palliative care hub', they recognise that they are just one part of the care jigsaw, working towards an integrated care pathway. Partnership working enables them to reach more children and families and to provide a more holistic approach to care provision. The children's hospice chief executive is on both the local and the regional network along with a range of other providers. The network has accountability to the children and young people's board within the SHA. The network underpins Richard House's work to deliver seamless, high-quality children's palliative care through their range of partnerships in the community.

The Government and user-led organisations have supported this approach, which can also be cost effective for providers.

## Commissioning

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Effective service delivery needs effective commissioning. It is important to ensure that the services commissioned reflect the needs of the community and, in the case of disabled children, multiple agencies are involved in commissioning services. It follows that all the agencies need good relations and communications to overcome important barriers to accessing excellent services.

Recently more organisations have been developing joint commissioning strategies. Evidence shows that commissioning is most effective when health and social care have joined forces to provide an integrated service for disabled children and their carers and family members.

### Case study: Seamless commissioning in Kingston

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An example of effective commissioning of services can be seen in Kingston, in south west London. NHS Kingston (the local PCT) and the Royal Borough of Kingston upon Thames have joined forces.

The key elements of the integrated service are:

- through the appointment of a single manager who is funded by both organisations, Kingston has been able to develop integrated services for disabled children
- a joint board, accountable to the Children's Trust Board oversees service delivery
- all services are being co-located into a new development which will be opened in the autumn of 2009
- capital costs have been shared between NHS Kingston and the Royal Borough of Kingston Upon Thames
- there is a jointly agreed service and the PCT and the council are pooling budgets with a vision of seamless commissioning. The two organisations agree the priorities for this service and the funding contributions from each organisation make up the pooled budget. The total budget is used to meet the needs of individual children, thereby avoiding arguments over who pays for what.

# Viewpoint

Disabled children represent up to 18 per cent of the child population, a number that is increasing rapidly as is the cost to the NHS of providing services which meet their needs and those of their carers. In most cases, a well thought out plan, specifically designed for the needs of the individual child, can improve outcomes as well as reduce costs for the NHS.

The profile of health services for disabled children has recently been raised up the Government's agenda. The NHS Operating Framework states that children are one of the four national priorities for the NHS. The Government has committed £340 million in NHS allocations over the three years from 2008/09 to 2010/11 to improve services for disabled children, including palliative care.

However, there is a need to show how all of these developments link together to deliver better outcomes for disabled children and their carers. PCTs are required to publish a statement in the autumn setting out their service plans for disabled children. The appendix on page 16 summarises the guidance produced for SHAs to use as part of their discussions with PCTs.

Having the appropriate tools and relationships to commission services for disabled children should mean that commissioners are better placed to commission high quality, cost-effective and appropriate services for all areas of children's services. PCTs need to better understand their local disabled children population and be able

to accurately report on the services they are providing to that group, in order to understand how well they are delivering 'more responsive services' as expected in *Healthy lives, brighter futures*.

A first-class service can only be delivered by first-class professionals. Although there are many examples of good practice and high standards of professionalism across England, evidence shows that the level and quantity of training could be improved so that frontline staff have a better understanding of the needs of disabled children.

Evidence shows that the best way to commission effective services for disabled children is when PCTs and local authorities work in partnership. Local authorities and PCTs already have a duty to cooperate as part of the local children's trust and partnership working in this area can lead to improvements in information sharing and cooperation overall. Many of the services outlined in the report are delivered in conjunction with other providers, particularly from the third sector. Developing long-term, meaningful and open relationships with the local third sector when assessing needs, commissioning services or planning new models of delivery for disabled children and young people, is therefore of prime importance.

To comment further on the issues covered in this report or for further information, contact Patricia Suarez, Senior Policy and Research Officer, at [patricia.suarez@nhsconfed.org](mailto:patricia.suarez@nhsconfed.org)

# Appendix– guidance to produce autumn statements

The DH has required PCTs to prepare a local statement setting out their service plans for disabled children. The statements must be made public by 30 September 2009. The DH's view is that these statements will enable local review and challenge with partners, service users and the wider community.

SHA children's leads have developed a set of questions to use when discussing the content of the autumn statements with PCTs. Taking this guidance into account, PCTs may want to consider the following areas when preparing their statements.

## General questions

1. What services do you commission jointly within your children's trust arrangements?
2. Do you have any collaborative commissioning arrangements with other PCTs?
3. How are you identifying and responding to the needs of disabled children and young people?

## Service-specific questions

PCTs may want to draw their attention to how they commission the services below, as well as whether these are included in their planned developments in 2009/10 or 2010/11. This includes specifying new PCT investment to support specific service areas in both 2009/10 and 2010/11 and identifying local gaps in services<sup>23</sup>. It will also be important to explain if there is any funding to support the service and whether a local gap has been identified.

1. 24 hour a day, seven day a week community children's nursing allowing children to be looked after in their preferred setting
2. Wheelchairs (powered/non powered)
3. Short breaks
4. Health key worker arrangements
5. Specialist palliative care
6. Equipment
7. Workforce development
8. Integrated assessments
9. Integrated services
10. A transparent service standard in service specifications

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- 23 Letter from Christine Beasley, Chief Nursing Officer. [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_104641](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_104641)

# Acknowledgements

*disabled*

## Every Child Matters

Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for disabled children. EDCM wants all disabled children and their families to have the right to the services and support they need to live ordinary lives. All disabled children will require health services throughout their lives – whether they are universal, targeted or specialist services. However, disabled children in England face inequality in access to the range of health services, and EDCM is calling on central government and PCTs to take action to tackle this situation. More information about EDCM's Disabled Children and Health campaign can be found at [www.edcm.org.uk/health](http://www.edcm.org.uk/health)

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# Aiming high for disabled children: delivering improved health services

Ensuring children and young people grow up healthy is a priority in any society. The Government has indicated a growing interest in ensuring the needs of children in the UK are taken into account when designing services, including healthcare services.

There are around half a million disabled children in England, a figure that represents up to 18 per cent of the child population. The NHS spends a much higher proportion of its budget ensuring that disabled children have their needs met than providing services for their non-disabled counterparts.

Providing effective health services for disabled children will improve outcomes for them and their families, ensure the child receives the best quality of care and provide better value for money. This report examines best practice around the country. It draws on examples of services for disabled children that meet users' needs, respond to the government agenda and are effective from both a quality and a cost point of view.

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