

Gateway reference: 12395

21 August 2009

To: SHA Chief Executives

CC: SHA Directors of Performance  
SHA Children's Leads

### **PCT Autumn Statements for services for disabled children**

The Child Health Strategy published in February 2009 emphasised the need to ensure that high quality, timely and accessible support is available for children and young people with acute or additional health needs and their families. It confirms that nationally £340m is included in PCT baseline allocations for disabled children for the period 2008-09 to 2010-11, to support implementation of *Aiming High for Disabled Children* and the children's palliative care strategy, "*Better Care, Better Lives*", to deliver improved experience for disabled children and their families in line with PSA12 on child health and wellbeing. This is in addition to the previously announced revenue funding for local authorities (£340m), over the same period.

David Flory and I wrote to PCT Chief Executives on 2 April 2009 (Gateway reference: 11593) setting out a specific requirement for PCTs to prepare a local statement setting out their service plans for children with a disability covering short breaks, community equipment, wheelchairs and palliative care, as part of the Vital Signs reporting arrangements. Since then David Flory has written to PCT Chief Executives, copying you in, on 30 July 2009 (Gateway reference: 12341), about reports on current performance on Vital Signs and plans for the future.

The purpose of the approach David has outlined is to enable local review and challenge with partners, service users and the wider community of the 2008/09 position and of the action taking place in 2009/10. It will also provide the basis for local discussions on priorities and areas for joint working in 2010/11.


SHA Children's Leads have come together to support work on the Vital Sign Local Priority Tier 3 indicator:

#### Parents' experience of services for disabled children

They have developed a set of prompts in the form of a template (attached), which can be used as part of your discussions with PCTs as you see fit in line with the development of their local statements on services to disabled children. The template covers commissioning arrangements and key actions.

I hope you will find this work helpful in your dialogue with PCTs as they work on their specific statements now and as they plan for the future in this important area of work.

Yours faithfully

  
Christine Beasley  
Chief Nursing Officer

## **CHILDREN AND YOUNG PEOPLE WITH DISABILITIES, COMPLEX AND PALLIATIVE CARE NEEDS PERFORMANCE NARRATIVE.**

PCTs have an important role to play in commissioning services for children and young people with disabilities, complex and palliative care needs, ensuring an integrated approach which improves outcomes. PCTs, as members of Children's Trusts, will be working with partners to identify the needs of this client group and commission appropriate services. This framework seeks to facilitate this process and to identify the NHS contribution to specific elements of these services for which additional national baseline funding was received by PCTs for 2008/09 to 2010/11. Some additional information on these services (community equipment, wheelchairs, short breaks and palliative care) is/will be available in the national children's services mapping dataset. To view relevant information available already through this route go to [www.childrensmapping.org.uk](http://www.childrensmapping.org.uk) .

Data pertaining to the national indicator about parental experience of services for children with disabilities will be available for 21 PCTs by September 2009 and for the remaining PCTs by December 2009. This framework may be completed in the context of that indicator and as a tool to help identify actions and developments which may improve performance against it.

**NAME OF PCT – NHS North Yorkshire & York**

**Commissioning arrangements:**

<p><b>Describe the aspects of services for children with disabilities, complex and palliative care needs which you commission jointly within your Children's Trust arrangements</b></p>	<p><b>Joint packages of care with LA providing regular care at home and respite care both at home in others homes and in residential settings. Supporting children accessing short breaks and leisure activities through aiming high initiatives. Palliative care services accessed at local Hospice. NHS continuing care supports children in school with joint funding with education.</b></p>
<p><b>Describe any collaborative commissioning arrangements with other PCTs for aspects of service (eg high cost low volume provision such as specialist equipment, specialist palliative care services, etc)</b></p>	<p><b>NHS NY &amp; Y has access to oncology service provided by Leeds Hospital for children and accesses Buterwick Hospice in North Tees for young children. Three way funding provides specialist equipment in foundation stage (non maintained) private settings. Through the Regional Specialist Commission Group, NHS NY &amp;Y have recommended a collaborative approach to the commissioning of palliative care services from Martin House Hospice in Wetherby, this service is accessed by 14 PCTs, this currently work on-going.</b></p>
<p><b>How is the PCT identifying and responding to the views of children and young people with disabilities, complex and palliative care needs and their carers?</b></p>	<p><b>Joint workshops have been held with parent and young people's representation. Questionnaires have been sent out to families and services users both from PCT and LA. Feedback from these have been used to identify needs. Client and carers views are identified and considered</b></p>

	<p>during individual assessments and ongoing reviews. By working in partnership we try to tailor make packages to meet individual needs. In North Yorkshire there is a Parents Forum for carers to express their views and VIP (Voice Implementation &amp; Participation) group that is multi agency plus parents, county council and young people members. <i>In City of York there is a well established parents group known as CANDI and they are represented on many of the key stakeholder groups around children with complex needs and disabilities.</i></p>
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SERVICE NEED	PLEASE INDICATE WHETHER THE PCT COMMISSIONS THIS SERVICE, RELECTING CURRENT EXPENDITURE	WHAT ARE THE LOCAL SERVICE GAPS? Are these identified in the Children and Young People's Plan?	NARRATIVE ON PLANNED DEVELOPMENTS IN 2009/10 INCLUDING NEW PCT INVESTMENT TO SUPPORT THIS	NARRATIVE ON PLANNED DEVELOPMENTS IN 2010/11 INCLUDING NEW PCT INVESTMENT TO SUPPORT THIS
1a. 24 hour a day, 7 day a week community children's nursing service enabling children/young people to be cared for in their preferred setting				A service is commissioned but there is not currently a 24 hour 7 day a week children's community nursing service. The community nursing service operates between the hours of 8am and 6pm Monday to Friday. All children on the caseloads do have open access to the children's ward at the nearest hospital to locality and can ring for advice at any time. There is no "on call" service from CCN team except in exceptional circumstance when they know a child is near end of life and they then offer extended support and this is on an individual basis. On call pilot to be evaluated in spring, so far numbers have been low for this service.
2a. Powered wheelchairs for children and young people				Powered wheelchairs are available to children. At present there is a waiting list. At this time, in one locality they are struggling to provide due to staff shortages.

<b>3a. Non Powered wheelchairs for children and young people</b>	Non powered wheelchairs are available for children and there is an assessment process to follow. The average timescale can vary from 2 days e.g. for a self-propelling wheelchair to accommodate a child with a broken leg to several weeks for other more specific longer term requirement.
<b>4a. Health service element of short breaks for disabled children and those with palliative care needs</b>	Health care support is provided through some establishments to support existing short breaks activity. Some health care training is available to those providing short breaks. This is currently being reviewed to establish requirements across all levels of training including complex care needs and palliative care.

Finance: Short breaks funding is available in 2009/10 on both a revenue and capital basis. Total available is £1.4m. 2010/11 funding will be decided as part of the 2010/11 operating plan process and so is not available at present.

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5a. Health key worker arrangements for children/young people who require health care packages in the community	<p>A health key worker is identified within the Specialist Community Children's Nursing Team, CAMHS Team or Children's LD team; this is being reviewed to ensure equitable access across the PCT area.</p> <p>A key worker identified in the NHS Continuing Healthcare team for complex care packages at home.</p> <p>A key worker identified to work with schools (usually the School Nurse or Specialist Nurse e.g. Diabetes or Epilepsy); this to be reviewed to ensure equitable access across the PCT area.</p> <p>At this time there are some gaps in training provision, this is being assessed and action plan to be developed.</p>			
6a. Specialist palliative care provision for children	<p>Children with oncology related illness are supported and can access the oncology service via Leeds Hospital but those with other life threatening or limiting illness or disease rely on the limitations of the CCNT. In some localities the adult palliative care service will support children over the age of 16.</p> <p>Community based specialist palliative care is provided by local acute hospital outreach in Scarborough, Hambleton and Richmondshire and York localities. In Craven and Harrogate this is provided by NHS North Yorkshire and York Community and Mental Health provider.</p>			

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1b. Year on year reduction in delayed transfers of care due to unmet equipment or community	<p>There is limited evidence available to identify previous delays and whether there has been any reduction in these delays.</p> <p>Specialist equipment is considered on a case by case basis at the specialist equipment panel meeting (held monthly).</p>			

nursing needs	<p>There can be delays between the time frame in which funding is agreed and equipment being delivered; this is mainly dependent on the individual manufacturer.</p> <p>Equipment utilised for a child will transfer with them into adult services; as appropriate.</p> <p>There is sometimes a gap in arrangements/agreements for children who may transfer in or out of North Yorkshire and require specialist equipment. These are mainly around confirming who is responsible for funding, provision and maintenance.</p>
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2b. The provision of equipment for individual children/young people in more than one domestic setting if requested.	<p>Equipment can be provided in more than one domestic setting; if required.</p> <p>There is a mixture of funding streams which are accessed to fund equipment for children in 1 or more domestic settings.</p> <p>At present there can be gaps in process, signposting, assessment and service standard specifications. If equipment is not provided in more than one setting and parents /carers are expected to transport it there is a risk regarding moving and handling.</p> <p>In response to Aiming High and in line with the availability of short breaks funding the commissioning of requirements around additional equipment is being reviewed.</p>			
3b. An NHS workforce able to contribute to delivery of the full service offer in short break arrangements	<p>Currently there is ongoing work to map skills of existing workforce and identify any training and development gaps.</p> <p>All levels of workforce from universal to specialist are included and training levels from generic to 'training around the child' including moving and handling.</p>			

4b. Free health skills training for short break providers from outside the NHS	<p>There is ongoing work with Local Authorities to identify and provide appropriate training for short break providers to enable more children and young people to take advantage of these short break opportunities.</p>
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<p><b>5b. Community children's nursing which integrates with other service providers, e.g. education, social care, leisure etc</b></p>	<p>Some but not all CCNT integrate with other service providers. Three of the teams are commissioned from Acute services and only one community team in NY &amp;Y Community and Mental Health services. Two teams include LD nurses and others have specialist school nurses based in special needs schools. There is close working with Local Authorities but this is limited with leisure service providers. There are some gaps in the provision of training. The specialist Community children's team in Harrogate work very closely with Local Authority (LA) establishments and schools to deliver appropriate training to meet the needs of children with complex health care needs.</p>
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<p><b>6b. Holistic, integrated assessment which includes a mobility assessment and leads directly to</b></p> <ul style="list-style-type: none"> <li>a) provision of an appropriate wheelchair if needed</li> <li>b) provision of appropriate community equipment if needed</li> </ul>				<p>There are integrated therapy services; the Physiotherapist (health) and occupational Therapist (LA) undertake assessments for equipment. Specialist equipment is provided/purchased from NHS Continuing Healthcare if it is deemed essential and leads to direct provision. Some specialist equipment which is requested as a preferred item and is expensive is referred to commissioning exceptional equipment panel for approval. In 2008-09 actual spend was £58,600 and is projected to be higher in 2009-10.</p> <p>There are limited clinical staff to meet the demand in referrals for wheelchair assessments; therefore cases are prioritised based on condition, life limiting illness and those who are full time users.</p> <p>Going forward NHSNY&amp;Y are aiming to commission an integrated equipment store to provide standard equipment direct. If this is successful it will shorten waiting times and will ensure all equipment can be audited and be maintained, serviced and repaired via one system process.</p>

	Individual assessment for bespoke equipment such as sleep systems and moulded seating will continue.
<b>7b. A transparent service standard in service specifications regarding 'time from initial assessment to receipt of fully functional/adapted wheel chair'</b>	<p>There have been few performance indicators to evidence the waiting times for specialist equipment but it is planned that this will be rectified and in place by the end of the financial year by means of accessing an improved database system.</p> <p>Service specifications are being developed and will be agreed with clear service standards.</p>