

AUTUMN STATEMENT for services for disabled children – October 2009

NAME OF PCT: NHS Gloucestershire

PCTs across England have been asked to produce a statement on services for disabled children by DCSF and Department of Health.

These statements are expected to set out the actions that the PCT is taking, either alone or in partnership, particularly in the 4 areas of:

- Short breaks
- Community equipment
- Wheelchairs
- Palliative care

Below is a table which provides detail in response to specific questions posed by Department of Health/NHS South West. The actions detailed in the table should be considered in the broader context which follows.

NHS Gloucestershire (NHSG) is an active partner within the Gloucestershire Children & Young People's Strategic Partnership (CYPSP) which is the Gloucestershire Children's Trust arrangement.

A Commissioning Strategy for Children with Disabilities was developed on behalf of the CYPSP during 2007/08 and children with disabilities have appeared in the two Gloucestershire Children & Young People's Plans 2006-2009 and 2009 – 2012; both of which have been adopted by NHS Gloucestershire along with the other partners of the CYPSP.

Gloucestershire is a pathfinder area for Aiming High for Disabled Children Short Breaks, and is also a pilot area for individualised budgets for disabled children, both of which represent partnership working between NHS Gloucestershire and Gloucestershire County Council.

NHS Gloucestershire's Strategic Plan 2009-2014 includes a range of strategic principles and objectives which include the provision of care closer to home for all users.

The NHSG principles for commissioning and service improvement for children and young people include commitments to:

- Deliver local services which are joined up across agencies
- Allow for early assessment and intervention to help prevent these needs becoming more serious, with a clear pathway to early multi agency support
- Meet children and young people's needs in universal settings wherever possible and always at the lowest level of service appropriate to need
- Support access to specialist support as necessary on a step-up, step-down approach
- Provide very specialist help as close to home as possible, supporting children and young people in their local network of family, friends, community and schools wherever possible.

This is also within a general resource context that expects investment and improvement to be delivered within the overall financial resource currently used for children and young people and consistent with any targets and expectations on cost efficiencies.

NAME OF PCT: NHS Gloucestershire

Commissioning arrangements:

Describe the aspects of services for children with disabilities, complex and palliative care needs which you commission jointly within your Children's Trust arrangements

There is strong partnership working between social care and health care commissioners, evidenced by a joint county council (GCC) and PCT (NHSG) Head of Joint Commissioning for children, young people and maternity, who manages an integrated commissioning team.

This is supported by meetings between NHS providers, commissioners and the voluntary sector.

NHS Gloucestershire (NHSG) has as one of its strategic objectives the provision of 'more integrated services closer to patient's homes.'

For services for CYP, this has led to the development of principles for commissioning and service improvement which emphasise joined up/integrated provision across agencies; and providing support as close to home as possible, and in the network of the child's family and community.

During 2007/08, a commissioning strategy for children with disabilities was developed '*You don't understand what it's like: improving outcomes for children and young people with disabilities*' on behalf of the Gloucestershire Children and Young People's Strategic Partnership (CYPSP) which is the Gloucestershire Children's Trust arrangement. This identified 3 key priorities for action across partners, including the health service as follows:

1. Meeting more of the needs of disabled children in universal and mainstream services with appropriate support, and supporting inclusion in their own communities, in line with the requirements of the Disability Discrimination Act and Disability Equality requirements.
2. Improving the level and impact of participation of children,

young people and parents in planning and commissioning services, and the promotion of services that give parents and young people more control.

3. Improving access to timely and appropriate targeted and specialist support through investment in key areas and more effective use of existing resources, with an emphasis on preventative services and services that promote independence, and a smoother transition to adult life.

Implementation of this strategy has been supported by priorities in the Gloucestershire Children and Young People's Plan (CYPP), which is supported by NHSG.

As part of the implementation of this strategy and the CYPP, there are several key initiatives underway aimed at helping to improve outcomes for Children and Young People with disabilities, complex and palliative care needs and their families.

This includes use of £1.6 million DCSF funding as a pathfinder area to transform short breaks provision including through a joint GCC/NHSG residential short breaks tender.

Consultations have demonstrated that parents and children with disabilities want high quality short breaks that are easier to access, more flexible than traditional short breaks and are fun and safe to use. The pathfinder project is designed to ensure that a full service offer for short breaks will be in place by 2011 that transforms the provision of short breaks for CYP and families, offering a greater volume and wider range of options, including by using universal provision.

The PCT is also working with GCC on initiatives to ensure early and sustained intervention for children with disabilities. These include nursing support for children and young people (CYP) using short breaks and who have continuing care / health needs.

The Community Lead Professional Team (GCC) has been set up to provide a simpler and speedier route for those whose needs do not require a social worker.

In addition, a pilot is being jointly developed between NHSG and GCC for individualised budgets for disabled CYP in order for families to have more control over the care they receive. This will specifically include studying how the health care needs of CYP could be met within an individualised budget through traditional or alternative sources.

Over the past few years, the level of physical and medical care needs of young people being assessed as needing the GCC Family Link (family-based overnight short breaks) service has increased. As a result £84k per year is being used to fund nursing and OT support for the Family Link service. In this way it is intended that nursing and OT support services will enable Family Link to provide support to greater numbers of children with disabilities who require nursing support.

A Children and Young People's Palliative care strategy is currently being developed, drawing on the expertise of a multi-agency and user representation steering group. Draft recommendations for commissioning palliative care for CYP will be available by the end of December 2009 that will include how hospice care is to be commissioned and how local services and pathways should be restructured. Cost pressures associated with any recommendations will be identified and subsequent work in early 2010 will outline how resources in other parts of the system can be released to meet these needs.

In summary, by 2012 we want the health needs of disabled CYP to have been met through timely response by universal, targeted and specialist services, as close to home as possible, with smoother transitions in place to adult services. We also intend to build on the strong collaborative working within children's trust arrangements and move towards more aligned or pooled budgets and integrated care.

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| <p>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)</p> | <p>The South West Development Centre is coordinating a regional approach to children's hospice care and palliative care within which local PCTs across the south west will be able to operate. NHSG is directly involved with these developments and the aim is to develop a regional framework by April 2010. Our local strategy is being developed consistent with this regional approach.</p> <p>NHS Gloucestershire also co-commissions with other PCTs the supply of specialised wheel chairs from North Bristol NHS Trust. NHS Bristol currently leads this commissioning arrangement.</p> |
| <p>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?</p> | <p>The CYPSP commissioning strategy included consultation with CYP and parents/carers and practitioners on the gaps in provision, as well as their priorities for development/improvement.</p> <p>The views of parent carers, children and young people were also elicited from a local study in 2008 on their satisfaction of palliative care services. This information is currently being used to help inform the development of the palliative care strategy which is due to report at the end of December 2009.</p> |

| 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 |
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| <p>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</p> | <p>The PCT commissions a children's community nursing team (CCNT) at a SLA contract value of £495k. This service is for 5 days per week 0800-1800. On-call provision is provided for children with end of life needs.</p> <p>Additional community nursing and OT support has been commissioned to support CYP in accessing the family link service.</p> <p>A further £88k is budgeted for health care packages outside the contracted hours of the CCNT. Spend last year was in the region of £120k.</p> | <p>The CCNT is experiencing demand and capacity pressures due to the increase in children with complex health / continuing health care needs, and a shift in some activity to the community service from hospital. Demand on the frequency and length of short breaks provision is also increasing. The CCNT is currently not a 24/7 service and gaps in service provision are currently made up from bank / agency care for night time and weekends.</p> | <p>The NHSG Strategic Plan for 2009-2014 emphasises joined up/integrated provision across agencies; and providing support as close to home as possible amongst its objectives for commissioning / improvement for services to CYP. Work is being undertaken to analyse activity and resources to support a shift in service and resource from hospital / acute care to the community services including the CCNT. A new panel consisting of membership from NHSG and GCC is being used to enable an equitable access to nursing short breaks and continuing health</p> | <p>When the analysis of activity and resources is complete, exploration of savings within acute care and specialities will become increasingly more sustained potentially to fund additional capacity within community services, including the CCNT.</p> <p>It is anticipated that any additional spend in these community services will continue to be found from existing resources for CYP.</p> |

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| | | | care support packages provided by the CCNT. Any additional spend within the CCNT service will be from existing resources for CYP. | |
| 2a. Powered wheelchairs for children and young people | Expenditure in 2008/2009 for children's powered wheelchairs and seating systems was £154,610. | Access has been subject to local targets set by NHS Gloucestershire of an average 2 week wait which is consistently being delivered. All prescription is led by clinical needs. | Maintain current performance until a review in the SHA regarding referral to treatment targets (due to report in December 2009) informs otherwise. | Current performance to be maintained and adapted in light of any new targets. |
| 3a. Non Powered wheelchairs for children and young people | Expenditure in 2008/2009 for non powered wheelchairs and special seating was £174,400. | See 2.a | See 2.a | See 2.a |
| 4a. Health service element of short breaks for disabled children and those with palliative care needs | The CCNT provides nursing short breaks as part of its £495k SLA agreement. Historically the spend on short breaks has not been disaggregated between continuing health and palliative health care. £84k/year is being used for nursing and OT support for CYP using the Family Link service. | Demand for a wider range of short breaks continues to rise due to a combination of an increase in children needing this provision and rising expectations from parents or carers. | The panel process referred to in 1a above is designed to ensure more equitable use of resources, and efforts to free up resources from other parts of the local health economy will aim to address cost pressures (see also 1a above for details). Spend on continuing health care is being | Efforts to free up resources from other parts of the health system will become more sustained to meet cost pressures and to increase capacity to provide health service support to CYP using the larger number and wider range of short breaks. |

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| | NHSG joint funds the residential short breaks service with GCC in the sum of £234k. | | separated out from the health element of short breaks through close liaison between commissioners and the CCNT and the separation of these budgets. | |
| 5a. Health key worker arrangements for children/young people who require health care packages in the community | Every child and young person who requires care packages in the community has a health key worker from the CCNT. This is built in to the CCNT SLA of £495k. | The CCNT service is not 24/7 and while the key worker will proactively liaise with the PCT out-of-hours service and child's GP, a 24/7 CCNT team would greatly reduce the risks of inadvertent hospital admissions. | See 1a which details how capacity within the CCNT will be built. | See 1a which details how capacity building in community services including the CCNT will be sustained. |
| 6a. Specialist palliative care provision for children | NHSG and GCC do not explicitly commission a specific service for palliative care but do commission and provide other services that meet these needs. In addition to universal services, children with end of life / palliative care needs can receive support from: <ul style="list-style-type: none"> • Community Paediatricians funded by PBR. | NHS Gloucestershire is currently developing a children's palliative care strategy which involves identifying local service gaps. To date, educational needs within the CCNT, lack of psychology provision, and unsatisfactory capacity of on-call/out of hours provision has been identified. The appropriateness of all health, council and voluntary sector | The palliative care strategy will inform any recommendations for developments in late 2009-2010. It is anticipated that any additional investment will be from freeing up resources from other areas of health spend on children (see 1a). In the meantime, a framework for a / commissioning relationship with hospices is being | The palliative care strategy will inform any recommendations for developments. It is anticipated that any additional investment will continue to be sourced from other areas of health spend on children (see 1a). |

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| | <ul style="list-style-type: none"> • The Children's ward at GRH, funded by PBR. • Paediatric oncology providing both curative and palliative care. Funded by PBR for consultant activity and block contract for nurse specialist (but with no funding for 24/7 care). • Gloucestershire Community Children's Nursing Team (CCNT) provides day-time nursing care and an on-call out of hours support for children who require end of life care. • Overnight short breaks provision for children with disabilities provided by GCC and under contract | <p>(including hospices) services is being analysed as part of this strategy.</p> | <p>developed which will potentially fund care on a case by case basis.</p> | |
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| | <p>from Action for Children.</p> <ul style="list-style-type: none"> • Care packages either from CCNT bank nurses or from voluntary and private providers. These may be funded as single agency or jointly funded between NHSG and GCC. In 2007/08 35 children and families received this provision at a total cost of approximately £140,000 to the PCT. • James Hopkins Trust. This is a local voluntary sector provider who provides nursing support in the home and at their centre for children with life limiting conditions that are under the age of six. The | | | |
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| | <p>PCT and County Council jointly fund £50,000 for short break care.</p> <ul style="list-style-type: none"> • Input will also be received from various other services in the community including, CAMHS, social care services, dietetics, occupational therapy, physiotherapy, district nursing, hospital education service, speech and language therapy, health visiting, and general practice. • Services provided from the Children and Young People with disabilities team at GCC. These include “Family Link and Contract Carers”, the “Community Lead Professional | | | |
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| | <p>Team”, “Children and Families Team, and the “Looked after Children and Transitions team”.</p> <p>This list is not exhaustive and the palliative care strategy will include work that attempts to analyse all the potential care pathways, and redesign these where necessary.</p> <p>Note that the PCT does not currently provide any financial support to Hospices. However, children and families are known to use provision from Acorns Hospice in Worcestershire, Children’s Hospice South West based near Bristol, and Helen House hospice in Oxford.</p> | | | |
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| | PLEASE DESCRIBE WHETHER AND HOW YOUR COMMISSIONED SERVICES DELIVER THE FOLLOWING. | WHAT ARE THE LOCAL SERVICE GAPS? | 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 |
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| 1b. Year on year reduction in delayed transfers of care due to unmet equipment or community nursing needs | Expenditure on children's community equipment is through a Community Equipment Service. In 2008/2009 this was in excess of £230K. The CES is a partnership agreement and is accessed by health, social care and education. Performance is monitored via the Gloucestershire provider Partnership and delivers in excess of 98% of equipment within 7 days (national performance indicator). | No current service gaps but equipment budget for continuing health care is increasingly under pressure. | A more streamlined faster responsive electronic equipment ordering process in place for equipment for continuing health care. The CCNT make decisions in conjunction with social care teams and while the most cost effective solution is explored this is not at the compromise to the client. | The plan will be to maintain current performance in a climate of increased cost pressures. Any increase in spend will need to be found from within existing resources for CYP. |
| 2b. The provision of equipment for individual children/young people in more than one domestic setting if requested. | Equipment is provided for children who live in more than one domestic setting. | All need is currently being met, but cost pressures for equipment mean that pragmatic decisions sometimes need to be made to ensure only essential equipment is "doubled up". | Maintain current performance within existing resources and increasing demand. | Continue to maintain current performance. |

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| <p>3b. An NHS workforce able to contribute to delivery of the full service offer in short break arrangements</p> | <p>The CCNT is not 24/7 but proposals to build capacity are being explored. Allied health professional therapy services (OT, speech & language therapy and physiotherapy) are working either to trajectory or better than trajectory in terms of 2 week waiting times. This has a positive impact in terms of needs based provision, improved access and quality of experience.</p> | <p>Skills in palliative care have been identified as a gap within the CCNT; the palliative care strategy is developing proposals to meet these needs.</p> | <p>See 1a, 4a and 6a</p> | <p>See 1a, 4a and 6a</p> |
| <p>4b. Free health skills training for short break providers from outside the NHS</p> | <p>The CCNT provide training and assessments to care providers outside the NHS to ensure competence in providing short breaks</p> | <p>Ongoing capacity issues within the CCNT potentially compromise this function.</p> | <p>Building capacity within the CCNT.</p> | <p>Building capacity within the CCNT.</p> |
| <p>5b. Community children's nursing which integrates with other service providers, e.g. education, social care, leisure etc</p> | <p>Care packages for individual children are often jointly funded with GCC through a combination of provision from the CCNT, voluntary and private providers. Frequent multi agency meetings include education, social care,</p> | <p>Capacity issues as discussed. There is still a lack of integration of social and health care assessment processes. Assessments can often be made by several professionals on separate visits. More</p> | <p>Building capacity within the CCNT with existing resources. The PCT is actively exploring opportunities with its key partners to move towards aligning and pooling resources and delivering more integrated care.</p> | <p>Building capacity within the CCNT with existing resources. Further work expected in pooling budgets and integrating care provision.</p> |

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| | health and the voluntary sector. | integrated working with the Common Assessment Framework (CAF) is also needed. | | |
| 6b. Holistic, integrated assessment which includes a mobility assessment and leads directly to a) provision of an appropriate wheelchair if needed b) provision of appropriate community equipment if needed | a) Mobility assessments (which are carried out by an integrated OT service) are holistic and integrate with nursing and social care assessments. Eligibility criteria are currently being developed for wheelchair provision to ensure appropriate and equitable provision. b) Community equipment services are provided from an assessment of clinical or educational need. This is carried out by an OT (or community children's nurse in the case of continuing health care equipment). | While professional assessments integrate well with each other, too many separate assessments are still being carried out in a client's pathway (see also 5b). There is also no current provision for providing equipment for needs considered "social" rather than "health". Sometimes charities will "top-up" a client's prescription for higher spec equipment or additional equipment not identified as being needed in the assessment. This practice is inconsistent and can lead to inequity of provision across the county. | Sustain current activity, and agree eligibility criteria that will ensure equitable and appropriate provision. Any new developments and cost pressures will need to be cost neutral within existing resources for services to children. | Sustain current activity while responding to any new identified needs or demands. |
| 7b. A transparent service standard in service specifications regarding 'time from | The service specification for standard wheel chairs is 7 working days from time of initial assessment | Specialist wheel chairs are supplied from North Bristol NHS Trust. NHS Bristol is the lead | Sustain current activity and work with partner PCTs at refreshing the service specification | Sustain current activity and respond to any new identified needs or demands. |

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| <p>initial assessment to receipt of fully functional/adapted wheel chair'</p> | <p>to receipt of item. Current performance against this standard is running at 99%.</p> | <p>commissioner. There is currently no formal contract in place, and no service standard in the specification detailing time from assessment to delivery. There is an informal service level agreement which includes prioritisation criteria for new and existing paediatric patients. A local target was set by commissioners in 2008 to achieve a referral to assessment of 2 weeks which has been consistently met.</p> | <p>with more detail.</p> | |
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