#### **Aiming High for Disabled Children**

#### **Short Breaks Pathfinder Programme Bid**

The following details provide a summary of the short break service and are taken from a pathfinder programme bid.

Current short break services provided in Leeds						
Short break provision	Is a service provided? (yes/no)	Funded jointly (yes/no)	Funding body/ bodies	Est. total local authority expenditure on services in 2007-08	Est. total other agency expenditure on services in 2007-08	
<b>Residential Unit Services</b>		•				
Overnight stays	Yes	provided by both	LA (Social Care) and PCT	LA £755,330	PCT - £448k (Hannah House running costs)	
Day care or sessional visits	Yes, small preschool day provision provided by Health respite unit.	LA and PCT but it is separate provision				
Outreach service	No					
Family based overnight c	are			•	•	
Contract carers	Yes. Family Placement have 7 contract carers	No	LA (Social Care)	£327,202* total budget for Contract Carers and Family Link carers		
Overnight sitting services	Yes, Children's Continuing Care Nursing Team/ Family Placement team	provided by both PCT and LA but it is separate provision	LA (Social Care) and PCT	£113,191 total budget for family placement sitting services	PCT- £765k	
Family Link services	Yes. 75 Link carers	No	LA (Social Care)	£327,202*		
Family based day care						
Contract carers	Yes. Family Placement contract carers who offer overnight care will also offer some day care	No	LA (Social Care)	£327,202*		
Family Link services	Yes. Family Placement carers who offer overnight care will also offer some day care	No	LA (Social Care)	£327,202*		

<sup>\*</sup> total budget for Contract Carers and Family Link carers

Short break provision	Is a service provided? (yes/no)	Funded jointly (yes/no)	Funding body/ bodies	Est. total local authority expenditure on services in 2007-08	Est. total other agency expenditure on services in 2007-08			
Sitting or sessional services (inc. befriending)								
	Yes, Children's Community Nursing Team	Yes	PCT and LA (Carers Grant)	LA £22,000	PCT £52,225			
	87 approved sitters, provide sessions and some overnights and longer periods in the child's own home	No	LA (Social Care)	£113,191 total budget for family placement sitting services				
	Voluntary Sector contract and spot purchasing with agencies	No	LA (Social Care)	£ 245,000 block contract £43,860 Block contract, carers grant				
Other short break service	es	•	•	•	•			
	Martin House Hospice provides some respite	No	PCT		£147k (PCT grant to Martin House)			
	Direct Payments- there are 90 families in receipt of direct payments	No	LA (Social Care)	£360,300				
	Leeds Inclusion Support service – Supports the inclusion of disabled children in pre school, out of school and play provision	Yes	LA (Sure Start, Children's Fund, Carers grant) and PCT	Sure Start grant £75,0000 (Supports pre school and child care for working parents as well as play and leisure)  Carers Grant	PCT £19,500 Children's Fund £12,500			
	Weekenders – Specialist Voluntary play care provision at weekends	Yes	LA (Social Care and Carers Grant) Children's Fund	£25,500 Social care £60,000 Carers grant £17,000	Children's Fund £55,000			

Short break provision	Is a service provided? (yes/no)	Funded jointly (yes/no)	Funding body/ bodies	Est. total local authority expenditure on services in 2007-08	Est. total other agency expenditure on services in 2007-08
	Weekend residential breaks for disabled children	No	LA (Carers Grant)	Carers grant £9500	
	Vol sector and parents groups that provide short break activities	No	Some LA grants and fundraising by groups		

## Each pathfinder is expected to focus on 4 'learning themes' from a list of 20. Leeds has chosen to focus on:

- Ensuring that parents, children and young people are fully involved in the planning, commissioning and delivery of short break services – in keeping with the local core offer (A1)
- Building the skills in the short break workforce to deliver the Full Service Offer (C2)
- Securing sufficient, quality short break provision for severely disabled children and young people who have challenging behaviour as a result of their impairment (D2)
- Securing significant, cost effective short break provision by working effectively with universal services (F1)

## The contribution which Leeds would make to learning as a pathfinder is outlined as follows:

- 1) There is a wide range of short break provision in Leeds provided by the Local Authority, PCT and Voluntary Sector. This includes specialist residential overnight services (LA and PCT), Home Based Services(LA, Voluntary Sector and PCT), a well established Family Placement Service and community based services which are joint funded and provided in partnership with the Voluntary Sector. A large number of families receive direct payments.
- 2) There is well established partnership working in the city. The Disabled Children's Inter-Agency Partnership leads on strategic planning, service development and joint commissioning of services for disabled children and is attended at a senior level. The group recently appointed a jointly funded programme manager to support the further integration and development of services for disabled children in line with key legislation and guidance. Priorities for the post are:
  - leading on a review of short break provision including further developing both specialist and targeted provision;
  - supporting disabled children and young people to access universal provision; and
  - further developing parent and child involvement and access to information about services .

The Partnership is therefore committed to developing and improving short break provision with the involvement of parents and families, and this work is already underway.

3) The programme manager has capacity to lead on the work and has experience in developing and integrating short break provision in her previous authority. This has included

developing community based specialist and targeted provision and supporting access to universal provision by developing staff skills through training and mentoring. This is an area Leeds want to develop, to secure significant, cost effective short break provision by working effectively with universal services, to ensure there is a range of provision to meet differing needs and that this is equitably allocated according to need.

- 4) Leeds is in a strong position to further develop inclusion in universal provision, particularly by improving access to, and availability of, inclusive play and leisure services which also provide short breaks: The city is making good progress in developing extended services and supporting inclusion in these with extended services representatives based in many special schools. One of the clusters is involved in a SEN Regional pilot in respect of inclusion in extended services. The Youth Service wants to further support inclusion; the Inclusion Support Service and Play Network have specialist staff that support inclusion of disabled children in play and leisure settings. There is a specialist sports service and a wide range of voluntary sector provision (such as weekend and holiday play schemes) in the city. Leeds is piloting the budget holding lead professional and wants to enable families to access a basic level of community based short break provision through a CAF completed by a lead professional who can access an aligned or pooled budget to fund any additional support. A work stream is being established to progress this, with parent representation.
- 5) There is in place a multi-agency resource panel that allocates overnight provision in Health and Social Care. Allocation of resources will be developed to include access to universal and targeted services and ensure all resources are equitably and transparently allocated according to the child and families needs. To support this, assessments will better identify which families need specialist services and which can be supported by more preventative services. This will lead to specialist services becoming more responsive and flexible to families that need these, reducing family breakdown.
- 6) Leeds was one of the first local authorities to set up a family placement scheme for disabled children. It has a variety of services and has demonstrated its ability to recruit and support carers and provide flexible packages of care. Partnership working in respect of short break provision can be evidenced using the scheme as an example: There is a long standing protocol which is reviewed yearly with the Leeds Health Trusts to train Family Placement carers in nursing interventions and other partnerships include the Fire Service undertaking Fire Risk Assessments, the Community Equipment Service storing and cleaning equipment, and the children's OT team undertaking assessments. The Family Placement Service has identified the need for additional funding to recruit fee paid carers to target hard to place children with challenging behaviour, and BME carers.
- 7) The good practice that is already established in respect of health service staff supporting and training carers and staff in short break settings will be further developed to build the skills of the short break workforce. This will include partnership working with CAMHS and the Children's' Community Learning Disability team to support the inclusion of children with challenging behaviour in all settings, both in universal services but also carers and staff in targeted and specialist short break settings.
- 8) As part of a £5m Disabled Children's PFI programme, a 12 bedded short break residential unit is being replaced with a new single storey unit and a new 8 bedded residential unit is being built for Young People 14-18 with learning disabilities and challenging behaviour. It will link with the Adult PFI Independent Living Project to create a pathway to independence in adulthood. The skills of residential staff will be further developed and enhanced prior to the opening of the new units, particularly to meet the needs of children with challenging behaviours and to improve the quality of provision.
- 9) There is strong commitment in the city to involving parents and disabled children in service developments and parents are represented on many workstreams. A proposal for a parent

liaison post is in development and the Children's Information service are working with agencies to establish a Disabled Children's Information service and a newsletter which can support parents in meeting the needs of disabled children and identifying provision.

10) The above demonstrates Leeds' strong position to progress the short break programme to meet the Full Service offer by April 2010 and thus contribute to national leaning. The proposal to achieve this meets both the four specified learning themes but also the majority of the learning themes.

## There are a number of ways Leeds have developed an understanding of disabled children, young people's and parents requirements for short breaks:

- 1) A parent action group (PCA) has worked closely with the Disabled Children's Inter-Agency Partnership for many years as a partner in the planning, commissioning and delivery of services.
- 2) A parent support group, SNAPS recently undertook a consultation exercise with parents (over 100) in respect of short breaks and the key messages were that parents wanted :
  - To be involved in service developments
  - To have increased access to information about services,
  - Improved access to play and leisure opportunities, (both for parents to take children too, and for community based short breaks) and more short break provision in general
  - transparent and equitable allocation of short breaks

These issues have been incorporated into the review of short break provision and resulting strategy for development.

- 3) Parents have been involved in other consultations including planning for the new PFI residential units and developing the Carers Strategy, and are represented on a number of working/steering groups.
- 4) Referrals for Social Care and Health short break provision are via a Disabled Children's Integrated Needs Assessment, completed with parents and children, and presented to the multi agency resource panel. The panel allocates the most appropriate resource and monitors unmet need which is incorporated into future service planning.
- 5) There are a number of active parent support groups in the city working in partnership with services and a well established parent partnership service supporting the development of parent's forums in the five "wedges" in the city. A multi agency parent liaison post will support further parental involvement throughout the implementation of the Aiming High agenda and enable consultation and feedback on service provision with as many parent groups and individual parents as possible, and from all community groups. This will help ensure future provision meets the needs of all. It will develop a parent link/information exchange and work closely with the disabled children's information service.
- 6) There is a multi agency disabled children's participation worker in post who supports the involvement of disabled children in service developments. Disabled children have been involved in consultation about the new PFI residential units and the worker is setting up a disabled children and young people's forum which will link into universal young people's forums. This will work alongside the parent forums to ensure full involvement in service developments, and also incorporate the views of siblings.
- 7) Children who have overnight short break provision in a social care or health setting have six monthly reviews of their care package. This includes all professionals involved with the child and family, and parents are central to the process and their views sought. The child's input is welcomed and supported in the most appropriate way.

8) The regional pilot in respect of inclusion in extended services is providing resources to support professionals incorporate the views of parents. This will be extended across the city.

#### **PCT** commitment

The PCT is strongly committed to the provision of a full range of short breaks, working in partnership with the Local Authority and 3<sup>rd</sup> sector providers to ensure that the health needs of children receiving short breaks can be met in all settings. This includes support to non-Health providers, as well as the direct provision of a range of Health respite provision, and is reflected in our extensive expenditure in this area.

Our Children's Continuing Care Policy is an example of good practice, and underpins the provision of an extensive nursing respite service into children's homes, both in the day-time and overnight, supporting children with the most complex needs and technology dependant children. Leeds is participating in the National Children's Continuing Care Pilot, and will ensure that the new Framework is fully aligned with the best practice elements of our current process.

Leeds has invested in a 4 bedded purpose-built, dedicated Health respite unit, Hannah House, which offers residential respite to a wide group of children identified as having health needs using our ground-breaking Nursing Dependency Tool. The Unit provides short breaks, as well as some day care and day trips for the children. The PCT is currently developing a business proposal to extend the provision in Hannah House to 6 beds, to encompass both step down care for technology dependant children and additional respite.

All Health respite provision is allocated by a joint Social Services & Health Panel, to ensure that the full portfolio of provision in the city is fairly allocated according to need.

Leeds has a well established Children's Community Nursing Team which provides short day-time sessions (3 hours weekly) of respite to children and families with less complex health needs (ie not eligible for continuing care).

The PCT provides support to a wide range of non-Health providers to enable them to meet children's health needs in a range of settings, and training agreements are in place with statutory partner agencies. The PCT is committed to extending this approach to enable all children, regardless of their level of need, to access universal provision and opportunities for leisure and new experiences alongside their peers.

Leeds would be willing to work with Regional Commissioning Units to explore ways of improving the commissioning of short breaks.

# The following support needs have been identified to enable Leeds to become a pathfinder

A part time project officer to develop and implement a communication strategy in respect of the Aiming High agenda and Pathfinder programme and to support the Programme Manager in setting up information systems to ensure the reporting requirements are met.

Additional support in fully establishing the parent forums and children and young people's forums across the city and supporting the workforce in incorporating parent and child views into service developments. This support could be identified through extending the work being done in the SEN inclusion in extended services pilot