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## **BIG LOTTERY FUND (BLF)**

**HOME CARE FOR CHILDREN WITH LIFE THREATENING /  
LIFE LIMITING CONDITIONS  
IN  
NORTHUMBERLAND AND TYNE AND WEAR**

**Final Report**

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**“This is my lifeline – there is nothing else out there as an alternative. I can get depressed when I’ve had no sleep for a long time.”**

**Parent of child receiving BLF service**

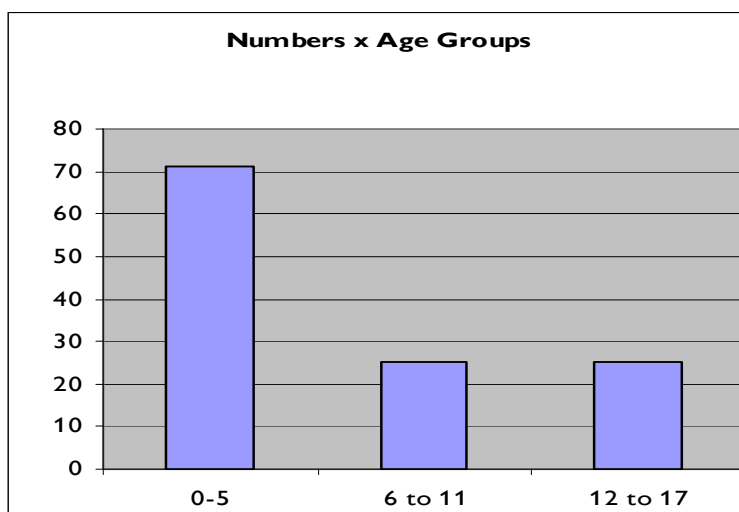
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## Section 2: Executive Summary

- In 2002 the New Opportunities Fund (NOF) Palliative Care for Children Programme was announced with 48 million pounds being made available to support the development and extension of palliative care services for children with cancer and other life limiting/threatening conditions.
- The NOF vision was to support a major expansion in palliative care services offered to children in their own home, and through new and expanded home based care teams provided by a range of health and social care professionals.
- NOF became the Big Lottery Fund (BLF) in 2004.
- Barnardo's Research and Development Team (North East) was commissioned by the BLF Regional Strategic Group to co-ordinate this evaluation.
- A BLF Audit Forum was convened to progress the Audit plan and the collation of the data that forms the basis of this report. This was a sub-group of the Regional BLF Operational Group which, in turn reports to the Strategic Group.
- The aim from the outset was to identify key issues and themes from all of the BLF services across the Strategic Health Authority. It was not the aim to compare and contrast the individual BLF Services.
- This report represents an account of the initial stages of the development of NOF/BLF services for Children with life threatening / life limiting conditions in Northumberland and Tyne and Wear up to September 2005.
- This evaluation did not explore the wider costs and benefits associated with these services. Some of the data, however, is suggestive of the wider impact of the services.
- The data was derived from a range of sources:
  - interviews with parents/carers
  - questionnaires completed by parents / carers
  - a workshop for the BLF workers
  - interviews with service co-ordinators
  - interviews with professionals
  - interviews with member of Strategic Group
  - minutes of meetings
  - information from workshops
  - NOF / BLF funding application forms
- The total number of service users supported up to 28th February 2005 was 121. The age breakdown of these can be seen in Diagram 1.

**Diagram 1. Analysis of numbers of young people supported by age (as at February 2005).**



- The main source of referral was CCN's
- The outcome data from parents/carers, questionnaires, service co-ordinators, professionals and BLF workers all told a similar "story". This should encourage confidence in the findings contained in this report.
- There was strong evidence, from the above data sources, of a range of positive outcomes for young people, parents/carers and siblings resulting from the BLF services which included:
  - For the child/young person:
    - Increased stimulation
    - Enhanced access to leisure activities
    - Enhanced therapeutic input
    - A wider range of people to relate to
  - For the parents/carers:
    - Time to attend to the relationship with their partner
    - Reduction in stress
    - Sign posting and resulting access to other services
    - Reduction in feelings of isolation
    - The ability to take part in leisure activities with the child and other siblings
  - For siblings:
    - Individual time with their parents/carers
    - Increased range of social activities
    - Reduced stress in the home

This impact has been achieved through the provision of the BLF workers. In particular, service users have commented on the workers' commitment, flexibility,

personal attributes, skilful work and the multi-purpose nature of their work which enables the service to address the needs of the children and young people in a holistic way.

Particular issues that would merit further discussion at this time include:

- The great emphasis placed by the services on the social needs as well as health needs of children / young people and the implications for future funding and delivery of the services.
- The suggestions for improvements made by parents/carers particularly in respect of access to the service over seven days and over night.
- In several instances, the lack of appropriate transport and social activities which has hindered access to social activities for children and young people.
- Aspects of the recruitment and retention of staff (in particular the link between the hours for which staff are employed and the flexibility of the service) which is impacting on service delivery.
- The effect on small staff groups of staff sickness and holidays.
- The extent to which the services in practice are jointly “owned” by health and social services and how this links to the issue of assessment, planning and coordination of packages of support.
- Further work on what the actual need for the services might be in the future, Current projections appear to be based on diagnostic categories rather than need as such.
- The wide range of tasks undertaken by the BLF workers which include both substituting for and extending existing service provision (i.e. CCN, Physiotherapy and so forth).
- The potential for developing the role of the “multi-purpose” BLF worker to expand multi-disciplinary resources in the community.
- The wider costs and benefits of the services including, for example, the impact of the BLF services on the increase or decrease in demand for other services e.g. short break care, community based multi-disciplinary services, hospital admissions, GP contact and so forth.

The Literature Review explored several important themes, related to effective service delivery for children with life threatening / life limiting conditions which emerged from the relevant literature, and links these to the aims of the NOF/BLF services and the research. Key themes identified include:

- Individualised care, negotiated with child and family, which is compatible with their lives.
- Technically competent carers, who have good interpersonal skills and insight into the family's situation.
- Effective coordination of service and continuity of care delivery.
- Opportunities for the child to access stimulation and social interaction, with increased access to activities outside the home (if appropriate).

During the period of this evaluation the Every Child Matters Outcomes Framework was launched (DfES, 2005)

Table 2 shows the impact of the services and the factors that have reduced the impact, summarised in relation to the Every Child Matters Outcomes Framework.

**Table 2. The impact of BLF services related to the Every Child Matters Outcomes Framework**

<b>Every Child Matters Outcomes Framework</b>	<b>Impact Evidence</b>	<b>Factors that have reduced the impact</b>
Be Healthy	Parents have been helped to ensure their children are physically and emotionally healthy	The main issue that has reduced the impact of the service on all of the outcomes has been either a reduced service or no service due to staff shortages (due to sickness or holiday)
Stay Safe	Reduced pressure on parents will reduce the likelihood of stress related abuse and promote security and stability of families and support parents in caring for their children	Transport has also been an issue with older children with complex needs
Enjoy and Achieve	Services have contributed to the personal and social development of young people and their access to recreation.	The availability of appropriate facilities has reduced the possibilities for socialisation
Make a positive contribution	Young people, their siblings and carers have been helped to develop socially and develop self-confidence	Limited 7 day and over night cover.
Achieve economic well-being	In some cases parents/carers have been able to return to work through support from the service. This will enhance the economic well-being of the family unit.	

Overall, these innovative services have demonstrated positive impact in line with their original aims and there is strong evidence of a range of positive outcomes for young people, parents/carers and siblings resulting from them.

## References

*Every Child Matters, Change for Children, Version 2, September, 2005, DfES.*

### **Section 3: Introduction**

This Interim Evaluation is the product of the work of the BLF Audit Forum and the BLF Operational Group.

The Audit Forum was formed in response to the recognised need to co-ordinate the evaluation of the BLF services across the Region. It developed out of discussions with the Operational Group. The minutes from the BLF Audit Forum are circulated to the Operational group and issues relating to the evaluation are regularly discussed with the Operational Group.

The group has comprised the following:

- Susan Musson, BLF Service Co-ordinator (the link to the Operational Group)
- Ann Macfadyen, Senior Lecturer, Northumbria University
- Christine English, Senior Lecturer, Northumbria University
- Jo Little, Service Co-ordinator, Gateshead and Newcastle
- Helen Little, BLF Worker, Gateshead and Newcastle
- Malcolm Stone, Senior Research Worker, Barnardo's Research and Development Team
- Sarah Armstrong, Northumbria and Northumberland Clinical Excellence Department
- Val Bagnall, Partnership Co-ordinator, St Oswald's Children's Service has attended and provided regular guidance and support to this group
- Occasional attenders from the Operational Group and Strategic Group.

The group has met on a bi-monthly basis.

The forum has been seen very much as "open house" with members of the Operational Group attending as and when they choose to. This has proved to be a fruitful forum for bringing together a range of expertise to progress the audit.

The forum has devised, monitored and progressed an audit action plan which has been shared with the Operational Group throughout the process.

Issues addressed at various stages have included:

- The aims of the Audit
- Gaining Caldicott approval
- Development of the Regional Questionnaire for service users
- Identifying different sources of information to identify the impact on service users
- Developing questions for the Service Co-ordinator interviews
- Supporting the BLF various workshops

## Section 4: Methodology

The data required by the commissioners, the data sources and the type of data collated can be seen in Table 4.1.

**Table 4.1. Data requirements and data sources**

<b>Data required by Commissioners</b>	<b>Source</b>	<b>Type of the Data</b>
<b>Description of the Original Services prior to NOF</b>	<ul style="list-style-type: none"> <li>• Original grant applications</li> <li>• Interviews with a member of the Strategic Group</li> </ul>	Qualitative Quantitative
<b>Description of the Services provided through the NOF programme</b>	<ul style="list-style-type: none"> <li>• Interviews with Service Co-ordinators</li> <li>• Minutes of the Operational Group meetings</li> <li>• Interviews with Service Users</li> <li>• Minutes of the BLF workers' workshop</li> <li>• Interviews with professionals</li> </ul>	Qualitative
<b>Identification of Pressures and Gaps within the Service</b>	<ul style="list-style-type: none"> <li>• Funding Application Forms</li> <li>• Interviews with Service Co-ordinators</li> <li>• Minutes of the Operational Group meetings</li> <li>• Minutes of the BLF workers' workshop</li> <li>• Regional Questionnaires</li> <li>• Audit forms</li> </ul>	Qualitative Quantitative
<b>Analysis of the difference made to children's lives</b>	<ul style="list-style-type: none"> <li>• Interviews with Service Co-ordinators</li> <li>• Minutes of the Operational Group meetings</li> <li>• Interviews with Service Users</li> <li>• Minutes of the BLF workers' workshop</li> <li>• Regional Questionnaires</li> <li>• Audit forms</li> </ul>	Qualitative Quantitative
<b>Perceptions of a range of professionals involved with the service</b>	<ul style="list-style-type: none"> <li>• Interviews with a range of professionals</li> </ul>	Qualitative
<b>Literature Review</b>	Northumbria University	

## **Data collation**

Data will be collated from the sources listed above.

## **Data analysis**

The primary data will be qualitative. Qualitative data will be analysed following the iterative process described by Miles and Huberman (1984) namely:

- Data reduction – selecting, focussing, theming and simplifying the “raw” data.
- Data display – organising and displaying the data in ways that allow for transparency in drawing conclusions (e.g. matrices)
- Conclusion drawing / verification – considering what the data “means” and verifying these meanings by such methods as triangulation to avoid bias as much as possible.

Quantitative data will be aggregated and presented in aggregate form using descriptive statistics.

## **Action research**

This project has followed an action research approach. Operational managers have been members of the Audit Forum and have been active contributors to the process.

Regular feedback has been given to the Audit Forum, the Regional Operational Group, the Strategic Group and local BLF worker workshops.

## Section 5: National / local background to the development of the services.

The New Opportunity Fund (NOF) was created in 1998 to distribute Lottery Grants for education, health and environment initiatives designed to improve the quality of life for people and communities, address disadvantage, encourage community participation and complement government strategies.

In 2002 the New Opportunities Fund Palliative Care for Children Programme was announced with 48 million pounds being made available to support the development and extension of palliative care services for children with cancer and other life limiting/threatening conditions. Palliative care<sup>1</sup> was defined as:

*'An active and total approach to care to children with life threatening/limiting conditions and their families. It embraces physical, emotional and spiritual elements for the whole family to enhance their quality of life. Symptom control, reducing emotional impact on family members, provision of respite care and bereavement care following death are all included.'*

Further, to assist with the process of submitting applications a definition of 'life limiting/life threatening' was issued by the Department of Health<sup>2</sup>:

*'Any illness or condition developed in childhood (before the age of 19) whereby the child is likely (a probability of greater than 50 per cent) to die prematurely (before the age of 40 years). Or any condition developed in childhood that without major intervention (which carries a significant mortality) will result in the child dying prematurely. Short term, acute illness and mental health diagnosis are excluded.'*

The NOF vision was to support a major expansion in palliative care services offered to children in their own home, and through new and expanded home based care teams provided by a range of health and social care professionals.

The Fund aimed to dedicate the resources to three different strands of the programme in the following way:

Home-based palliative care teams	£30.7 million
Bereavement teams	£2 million
Hospice provision	£15.3 million

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<sup>1</sup> Guidance Notes Palliative Care for Children Programme, New Opportunity Fund March 2002

<sup>2</sup> New Opportunity Fund on line guidance, Frequently asked questions, Definition of life limiting and life threatening illnesses in children, May 2002

To meet the NOF requirement of individual bids representing a population area of approximately 400,000 to 600,000 the six areas of Northumberland, Tyne and Wear divided into three:

- Northumberland and North Tyneside
- Newcastle and Gateshead
- Sunderland and South Tyneside.

This evaluation report relates to the 3 bids to the **home care strand** (above) submitted by local partnerships of health, social care and the voluntary sector in each area and co-ordinated by a 'regional' strategic group.

The Guidance Notes<sup>3</sup> (2002) for agencies submitting proposals for the Home Care Strand highlighted that NOF was looking to fund:

1. Multi professional community teams of peripatetic social workers. Play/art/music therapists and some consultant session time.
2. Respite Care or sitting services for children with life limiting/threatening conditions and/or their siblings in their homes to offer parents or unpaid carers a break. Services should be integrated with the home-based care teams for children and should offer services outside of the usual office hours.

The regional group focussed on number two above and in August 2002, grant requests of up to £400,000 over 3 years per area were submitted to NOF. The bids were successful with a total of £1179,465 being awarded for the Home Care Schemes early 2003 and the strategic group reconvened to oversee the implementation of the plans over the three-year period of NOF funding.

Table 5.1 shows, for each programme, the aims of the service, and details of numbers and type of staff employed.

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<sup>3</sup> Guidance Notes Palliative Care for Children Programme, New Opportunity Fund March 2002

**Table 5.1 Aims and staffing of the Programmes**

	<b>North Tyneside and Northumberland</b>	<b>Newcastle and Gateshead</b>	<b>South Tyneside and Sunderland</b>
Aim Of Service	To increase the provision of respite care to children with life limiting illness and complex health care needs in Northumberland and North Tyneside by developing a new role of child health care worker, who will work with and be supported by the Children's Community Nursing Team (CCNT).	To develop a high quality community based respite care service to children and their families with life threatening/life limiting conditions in Gateshead and Newcastle by building on the work of the children's community nursing team through inter-professional/inter agency working together.	To develop home based palliative care services for children that will: Provide both nursing and practical 'at home support' for children and their families Provide 'out of hours' services through the establishment of a regional network of palliative care programmes Provide sustained support to children and their families and help them access a range of other services – including hospice and bereavement services
Funded staff	37.5 hrs F Grade nurse. 187.5 hrs C Grade Child Health Carers	18.75 hrs G grade nurse for first year of project 150 hrs B grade carers	1.5 WTE community nurse – G Grade  150 hrs link workers: Grade B
Actual staff in post	37.5 hrs F Grade nurse. 130 hrs C Grade Child (we have given extra 30 hrs contact for 9 months to account for not being up to full establishment from start) 60 hrs C grade child recruited awaiting clearances.	G grade nurse in post for 12 months and ? how this will continue no – one in post at moment  92.5 hrs B grade carers	.5 WTE G grade South Tyneside .5 WTE G grade Sunderland  75 hrs B grade in Sunderland 18.5 B grade in South Tyneside and 37.5 C Grade

A member of the Strategic Group has described how the NOF/BLF funding has helped to progress ideas that were already being developed within the Region. Work

was already underway by a group of managers / practitioners with an interest in this group of children and young people.

Locally it was felt that:

.....these children were almost invisible in terms of strategic planning; nobody was really thinking about them either within their own organisation or between organisations.

The aims of the NOF funding fitted in well with local assessed need:

– It certainly fitted in beautifully in terms of gaps in service provision. So short breaks across the board whether they were family-based, residential or whatever was identified as a huge gap but that to me is only one gap in terms of planning services for children.

Section 5 gives further details of local assessed needs.

Processes to facilitate transitions for this group of children /young people have also been identified as a key issue:

There's lots of gaps still in terms of other services that children will need, complex health care needs and disabilities when they start to get older I'm thinking of transitional planning from toddler – different stages of transition. I don't think that works well, I don't think we've got a handle on that so I think we need to do a lot of work on that. I think when you come particularly to transition from children's services to adult services there is a massive amount of work needs to be done and I'm not clear yet that within NOF projects we've got the money but we're going to pick up some of these issues.

The hope is that the development of these services will facilitate multi-agency strategic planning for this group of children/young people. A concern is that, without input from both health and social care, the medical model of disability might predominate. Thus the way in which services are both planned and funded can affect the characteristics of the service and the model of disability adopted.

The need to clearly identify the particular needs of this group of young people has also been emphasised.

...you know if you look at the opportunities that we are all striving to provide for young disabled children which are around becoming independent, independent living, being able to have some sort of job, friends, the whole range of things we would all want, you've got this added dimension that actually this group of young people are not going to remain the same they are actually going to deteriorate so they have other needs as well, psychological support, emotional support, a whole range of needs ... they are a sub-set, if you like, of disabled children and we need to make sure we have got the strategic planning right for them.

## Summary

Within the Region the NOF/BLF funding is helping to progress an agenda that was already being developed prior to the funding coming on stream.

The development of the services is also bringing into focus:

- the nature of multi-agency working with this group of young people
- the relationship between planning, funding and the subsequent models of disability that come to characterise the services
- the particular needs of this group of young people at the various transition points in their lives
- the particular needs of this group of young people faced with the prospect of a deterioration in their conditions.

## **Section 6: Identification of pressures and gaps within the services that formed the basis for planning the current services**

In 2000, the Tyne and Wear Health Action Zone Children with Complex Needs Group commissioned an audit of respite and palliative care services for children with complex needs in Tyne and Wear. The following pressures and gaps were identified.

- Not all short break care services were available for children with Life limiting / threatening conditions.
- A co-ordinator located alongside the CCN team should be available to build up a skilled group of workers to provide Children with support in a range of activities.
- The need for a regional approach and the development of regional resources where there is shared value/vision and trust between respective partners.
- A flexible and sensitive service where carers are trained so that parents can feel confident that their child is in 'good hands'.
- The need for a 24 hour service especially in the terminal stage.
- Establishment of a multi agency training programme for staff working with children with life threatening illnesses.
- To receive help in meeting the needs of parents and siblings during the child's illness and during death and bereavement.
- The need for regular respite including nursing care and symptom management.
- The need for Health Education and Social Services working with children to work together to ensure purchase of appropriate respite care for children with complex health care needs. Agencies often 'pass the buck' as to whose responsibility this is.
- Joint assessment and collaboration in order to deliver care packages in the most efficient cost effective way that is both child and family centred.

### **Reference**

Castle and Lenehan, 2001, Audit of respite and palliative care services in Tyne and Wear for children with complex medical needs. The National Development Team and Council for disabled Children.

## **Section 7: Operational issues in developing the BLF services**

This section outlines the issues that have arisen from the various perspectives of the Service Managers during the implementation stage of the BLF services. The section “tells the BLF story” from the viewpoint of the Service Managers using their words as much as possible.

The source data for this section includes:

- interviews with Service Co-ordinators
- the minutes of the Operational Group

The section highlights key themes. It is important to bear in mind that this represents a point in time where the several BLF services are still developing and learning from their experiences.

The interviews with Service managers were undertaken in December 2004. The data from the Operational Group includes all of the meetings of this group up to and including March 2005.

### ***Why were these services developed?***

All of the managers referred to a group of young people who appeared to slip between the various sets of service criteria that existed prior to the BLF services being developed.

You had children who were severely disabled and could access services and you had children who had slight disabilities who accessed services and then these children in the middle almost, because they had a nursing problem, couldn't access anything and hopefully we are targeting these children.

There is a continuing discussion about what constitutes “need” and how this was assessed prior to the BLF services being developed.

... in the original bid– they were talking about 200 and more children over the three years but cystic fibrosis children had been identified, most of whom are generally very well...a lot of them are living way beyond what would have been possible a few years ago...so they are well children, they are at school, they are generally accessing mainstream services and they don't actually need our service at the moment. Not one of them has needed the service or asked for it....children with renal conditions were also listed originally but they are generally well children...similarly with cancer conditions ..... we have had no referrals from the cancer services but they've got a very good outreach service...

At a recent Operational Group Meeting comments were made when reflecting on the number of referrals so far:

... with these figures you can work out how many children there are with life threatening illnesses from the population and I suspect some of that was done and then they wrote to individual people but they didn't look at what

their needs were and assess their needs. They looked at what their condition was and it's no use saying that every person who has Down's syndrome needs to have cardiac surgery or whatever – you can't bring out figures like that. In the same way you can't say that everyone with a life threatening illness needs to have support in their home – it doesn't work like that. So no one had spent the time to try to get the figures to assess what the needs are...No one did that....figures don't reflect what a service requirement or service need is.

Choice has been an important consideration in the development of services.

... families had been identified who didn't really want their children to go into respite care, into a hospice or such, wanted something within the home so that they didn't feel that they were actually ... some families just don't want their children to leave the home environment but then they weren't able to just go out shopping, or even just have a break. Some of the mums were saying they were absolutely shattered and even to have a three hour sleep in an afternoon when we were there – and that's what some of the mums are actually doing just having a sleep and they were saying there was no service on an evening where they could do something on an evening when the children came in from school then that was it their evening was obviously spent with their child

Another important reason for the BLF services being developed included the need to enable some young people to be able to access short break care.

... they couldn't access short break care because of the nursing needs. Social services in both areas had a short break care facility but in order for the children to access the short break care they had to put nursing cover in, so it limited the number of children who could actually access those services plus there was also services like family-based short break care but it was very difficult to recruit families to that so we knew the needs but we couldn't meet the needs because there weren't families available who could actually take them.

This is perceived as being linked to the various restrictions placed on staff by current regulations.

... I suppose there are restrictions on what social care staff can do and some of those restrictions come from the local authority themselves but some of them actually come from health, which restrict what non-nursing carers can actually do. So there is an element of both that actually worked against the children accessing the services so they just didn't get them and if it was a family-based short break care we could teach the carers how to look after the children but there weren't enough of them around.

An interesting comparison has been made between young people with learning disability and those with a physical disability.

Yes, a lot of the short break care is, as in many areas, really based around learning disabilities. There might be physical disabilities but physical

disabilities might be around being too dependent or something like that but if they had complex care needs like tracheotomy or gastrostomy there was nothing? So some of the children with learning disabilities could access those services but again with another group of children with physical disabilities but not learning disabilities who couldn't access any services at all.....So there were two different worlds one with children with learning disabilities who were becoming more dependent on nursing needs and one with children with physical disabilities who could not access anything.

Socialisation has been emphasised strongly.

A lot of the bid was around socialising these children, trying to put in some normality to their lives as well – I suppose the knock on effect was giving the parents a break but it was more about these children stuck at home and nobody looks after them and their whole life revolves around their parents which isn't how it would be for other children.

A Service Manager reflects on the lack of referrals at the initial stages of service development.

It was the frustration, at the beginning, of what I thought would be masses of numbers of children didn't happen and then the nursery nurses were getting a bit frustrated at some point because they didn't have enough work. But I must say that has turned the corner because we are identifying more children. I think all of us were a bit like "What can we offer", and the criteria was very needs limited because they have to have a life limiting condition and one or other technical dependencies so the criteria at the beginning was a bit tight. We have stuck to that criteria because there were consultants saying "You've got nursery nurses can we do some potty training, can they do some play with a little girl who is just a bit hyperactive?" and if I said "Yes" to all of them we would have been swamped and that wasn't the idea.

A Service manager comments on how the service has developed to enable children to die at home where this is requested.

Yes and I think the other thing was to allow children to die at home if their parents wanted it and I think that was where there was a gap because apart from having a CCN like ourselves who would have been going in daily if the child was dying we can now offer a service where someone can go in and spend as much of the day as they need to spend there whilst the child is dying. We've only had the one but it went very well.

### ***Who are the Service Managers?***

The roles of the several Service Managers all vary considerably. Some are on fixed term contracts some have substantive contracts. Some are part time, some full time. Some are also CCN's who offer a CCN service to the BLF service and / or other service users. In some cases in their role of CCN, they refer service users to themselves in their role of Service Manager. One Service Manager's contract has already ended and in the case of this service the main stay of the service is an administrator. In one case the Service Manager role is very much that of allocating a

resource with little, if any, contact with service users. In other cases Service Managers are actively involved right from referral in meeting families, assessing, planning, implementing and reviewing the service and introducing the BLF worker. This should be borne in mind when considering the role of the Service Manager – there is not one role – there are several roles. All of these different roles have impacted on the development of the BLF services.

All of the Service Managers have been under pressure to get the services up and running.

... I think the pressure was almost from BLF to get this service up and running as soon as possible. You have a little picture in your head of how the service is going to look but you never know fully what it is going to be like before you start to implement it.

The service managers all come from varying backgrounds and for some working in the community has been a relatively new experience requiring personal development alongside the development of the BLF service.

... The main challenge for me was that I was employed at the end of September and two weeks later two of the health carers actually started and that was a huge challenge for me because I had never worked in the community before, I'd certainly never worked within the geographically area so I was almost then thrown in without having the opportunity to do networking and finding my feet and finding out a little bit more about the area and finding out a little bit more about these children.

It is important to note that not all of the current Service Managers were part of the teams that wrote the original bids and absorbing the original aims of the service has needed time.

I knew that the job was to set up the service. I wasn't prepared for what I had to set up. I think it was because I didn't have any part in the planning that I really didn't know what was involved and there again neither did my manager. Not my business manager, they obviously had their set ways in thinking how it was going to work because of their involvement in the planning process but my matron ... we really fumbled through a bit at the beginning.

Being both BLF service manager and carrying a CCN caseload has been seen, in some instances, as being beneficial.

... I don't think I would have learned what I have learned if I didn't have that caseload as well. I learned so much coming from a ward after so long on a ward, going into the community not knowing any of the things that go on in the community, taking on a new role that wasn't even set up and then trying to manage a caseload. It's been a huge learning curve.

In another instance the Service Manager has had no contact with BLF service users. She has allocated the resource (BLF worker) and then informed the CCN who would then introduce the worker and so forth.

I would read through and decide whether they fit the criteria, whether we could help this family, support them, what times we could offer because we mightn't always be able to offer the times that the family are asking for. Mostly we've tried to comply to that to some extent and then inform the named referrer – usually the nurse but actually from areas L and K we've had quite a few referrals that have come through the social workers and in K we've only had a couple – about four I think, and then get back to them to tell them whether the referral has been accepted or not accepted and why. I also then put that in writing and then arrange for the referrer who is usually the nurse to introduce the child and family worker to the family and take on any training needs there might be.

For some Service Managers being part time and playing multiple roles has resulted in tensions.

If it is something like yesterday it was a case of a worker rang me and I was having my lunch before going to a meeting and because a mum had rang her at her home and left a message to say that the child she takes to school wouldn't be going to school so she didn't need the BLF worker in the morning so she had to ring to tell me it had been cancelled and to ask how to deal with this. So I still have to sort those types of things out and I am not supposed to be doing that job. Even if K (administrative assistant) got the message K would ring me to check out with me because she isn't paid to make those decisions. These 'phone calls happen whichever job I'm doing.

Some Service Managers play multiple roles depending on whether they are full or part time and, if part time, what their other role(s) might be.

Some of it is – some of my caseload has the children within it who are using the BLF service but some of the other CCNs' children are linking into the BLF service so I am actually co-ordinating and facilitating that further. I both manage the service and also a practitioner within that service as well and actually going out and doing clinical work as well

### ***The various roles played by the Service Managers***

In this example the combination of the commitment of the Service Manager (who is also CCN) the BLF worker and the consultant on call enabled a child to die at home. It is described at length as all the details are relevant.

... it did work okay but that was purely due to commitment from me and one of the nursery nurses because I was going in and changing the medications which obviously are quite new to me syringe driver being set up and then just consultants ringing to say to alter this dose, alter that dose but the consultants were doing a night time visit so they were doing maybe an 11.00 p.m. visit – it was only the Saturday and Sunday night they had to do that but the nursery nurse was in for so many hours and I would go in for a couple of hours, do all the medication and support the family. Then on the Sunday she was there for so many hours and I went in for so many hours on the afternoon. On the Monday she was there all day with that family and

they wanted her there which was for moral support. On the Sunday when we thought the child was dying they didn't want us to leave but I had to tell them that we both had to come back tomorrow and it was 11.00 p.m. that night before we left that house. Learning from that, I was new in post and just wanting to know that this baby was comfortable I did stay but I think if I was in that situation again there would have to be a cut off time where we left because they wanted us to stay all night and I knew I couldn't do that.

That was a good weekend because we had a good consultant – there are two who are excellent and will come out. I don't know what would happen if it was another consultant on call. It might come down to the individual consultant. I was having to run back and forwards to hospital to pick up diamorphine and things like that. It wasn't until afterwards that I thought about changing the medications and they were talking about diamorphine and I was doing it because I knew it was what I had to do but I had no back up – it was a huge responsibility. That service if I evaluate that family it will just be glowing – it's not blowing our own trumpet it would just be that it was what they wanted from the beginning, they didn't want to be in hospital so we managed to keep them out of hospital, we provided the support service that they needed, we were there the next day when they were taking the baby away and that's what they wanted. Some families might have thought "No I only want you for an hour we can cope for the rest of the time" but that family wanted that and we were able to give it.

### ***Service Manager as Care Co-ordinator***

One way in which the Service Manager role has developed in some areas is into that of Care Co-ordinator.

I've found we all try to work multi-disciplinary with these families and the amount of people these families have coming is phenomenal and I have found that as a co-ordinator that I have taken on more of a role of co-ordinating what is going on with the different therapists so we try to do multi-disciplinary meetings to try to look at the child as a whole person rather than looking at speech and language or physio. So I hope it has encouraged more multi-disciplinary work and I have found with some, not all of them, but with some of the children I have taken on the lead almost to co-ordinate all of those things.

### ***Recruitment / retention of BLF Workers***

There appear to have been no problems recruiting staff to the BLF worker posts. A variety of workers have been recruited (**see Table 4.1**)

... we only advertised internally ....and we only had a response of three candidates which were all suitable candidates and were actually recruited but I think we potentially need to look at the way we advertise the next time because I think it is an interesting job and there are people out there who would respond. We didn't necessarily capture that by advertising internally but it is the cost of advertising – it's so expensive.

At this time no men are employed as BLF workers. Did any males apply?

... two men rang up and spoke to me and I really gave them all the positives and told them of the type of job it was and we need men because some of these are young lads that are going to be dealt with so we want men. We've got a male nurse on the team, and experienced nurse and I thought it would be great to have more men but they didn't turn up for interview ...

In one instance a family allowed a picture of their child to be used.

We actually got a fantastic response to our advert that went out. One of the families allowed us to use the child's picture and we had over 100 enquiries and about 60 to 80 applicants. Actually having to whittle it down to people you wanted to interview I think that quite difficult because we hadn't specifically asked for any qualifications although nursery nursing or an NVQ or something but we wanted more of these people with experience, people who knew what they were taking on, people who could offer the children the right opportunities and not just people who wanted to do it as a philanthropic kind of thing. We stopped the shortlist at 15 people and about 8 of them turned up – it was really weird so we actually had people who opted out at the last minute which then sort of reduced the numbers a bit.

Being part of existing networks has been seen to be particularly advantageous.

We have recruited internally. All of them are highly skilled, excellent staff, I couldn't have asked for better. I think we've been really lucky in that the people we've employed have really been the best thing about it – I can't praise them enough because they really both have such strong skills and abilities to be able to just get on and they interact so well with the families and because they had so many skills anyway when they came into it they were ready to just get going and they just wanted to get on with it. They were both part of existing networks in the health service.

For some recruitment has been very challenging.

We've now ended up with four workers – one person who is full time has had surgery and is still recuperating from that so we've had a vacancy of about 50/60 hours so we re-advertised again recently and offered one person a job because the second person didn't drive (this was put in as an essential). I have since been told that the person we offered the job to a week ago doesn't now want it. So your question about recruitment is a nightmare!

In one instance lessons from the first round of recruitment have been learnt as BLF workers have left and new ones recruited.

The workers that I've got at the minute are the kind of people who say to me "Well it's not about me it's about the family and what I can do for them." Whereas in the beginning we had people who didn't feel that way and fortunately they moved on. I think that is a success because we have instances of people who have never been in a caring role before and are obviously picking up these skills very well. In the first appointments we made

we had problems with two workers: They had different views of what the job was and they were quite difficult people to work with.

Another key issue has been the hours for which workers have been recruited. Initially many workers were recruited on full time contracts. The learning so far is that more staff on fewer hours offers more flexibility. This should help deal with the fact that the main time that the service is required tends to be early morning or early evening with slack periods through the day.

But the way we've decided to go to give more flexibility to the service – we've got three staff on 30 hours, one staff full time and one staff on 16 hours and we are trying now to mix so that we are just going to give anything from 7.5 to 15 hours per week contracts so that we can employ more staff on smaller hours just to try to give more flexibility and we will have them dotted around the area according to referrals and need.

### **Referral / assessment**

In the main at this time the majority of referrals are coming from health. This can probably be accounted for by the fact that most of the initial referrals have come through CCN's who are working directly with service users who meet the criteria for the service.

One service manager explains:

... most of these children were already known to the Children's Community Nurse team so when we started and had got the staff up and running and undertaking their training I then looked, together with the rest of the CCN team, at a potential caseload and the CCN's went out to the families and explained to them that there is a new service coming up, and asking if they would be interested in it and if they said "Yes" they were interested in it, then I would then go out and introduce the service.

And

... we haven't had any referrals from outside the CCN Team as it stands at the minute – I don't know why that is but we haven't and so all the referrals are from a CCN and we just discuss referrals in the team.

A different experience is described by a further Service Manager who comments:

Where do referrals come from? Probably consultants 80% and social services 20%.

The Service Managers play a range of roles in relation to the assessment process.

The most typical role is described thus:

I do an assessment which normally is quite a big assessment looking really more at the social circumstances of the child and I try to keep away from the medical side of it and just say 'how do you actually look after your child,

when you put him in the bath does he like bath toys, does he like bubble bath?' just break it down to simplistic things because I found that at the end of the day that was the main fear for these families – they had been completely 24/7 with these children and no one can look after that child the way that they can. So it was finding out about those little things which are such important things to make the child comfortable and most of these children are non-verbal so they cannot tell you themselves so it is really important, I feel, to get a really thorough assessment from the outset and then I usually allocate the staff and they will link in.

### **Staff sickness / holiday**

Sickness has been a real issue for some of the services. With small services such as the BLF services, any staff off sick or on holiday can have a significant effect on service delivery. There have been some occasions where some areas have had no staff available due to holiday / sickness.

... and in May one went off on long term sick who has just come back to work and hasn't actually come back as a carer because she feels that's not the job for her. So she works 30 hours a week, she came from hospital, she came from adults with very similar difficulties as the children but it's not the job for her, doesn't like the community and went off on long term sick. In July another went off on long term sick so we've had a lot of sickness because I think they don't realise how stressful it is actually going to be and it is stressful.

Yes, we haven't had anybody leave yet but we have had the two on long term sick which has caused problems because that was 60 hours per week down on our services.

And

... I had to write to them to say due to sickness the service will be limited and I thought that was probably a better way so that they know why the service is limited and I am just a bit frustrated that they are only getting a very limited service at the minute. Also you wonder because it is two whole time equivalents their hours are great but they are obviously restricted to days rather than three hours here, half a day there etc.

Another manager describes how she juggles with time to try to keep the service going in the face of sickness and staff leaving. She both covers herself and uses the wider CCN team to help out.

I have one worker who handed her notice in just after Christmas she left last week and we advertised and had a lot of what looked like potentially good candidates. We will be short listing next week. The other worker who was with the team from the start and then never actually came back to work with the team after she had gone off sick has now got a new job and we are just waiting for her notice. The other three, permanent staff, two definitely long term sick and the other one hopefully just short term sick. We have one nurse in area V who does four hours and a nursery nurse who is already

linked to the team but who is also doing some work for the team and we are just sort of back-charging and she is covering two families. I'm very tired by the time I've done some of the covering. Luckily the other CCNs in the team are going to do extra to cover so that we can at least keep it going for those families ...

The impact of staff shortage on families' commitment to the service has also been noted:

Although we invest a lot of time, the families invest an awful lot of time – they are used to going off and doing whatever with their children, they've then got to spend the time teaching the health carers about that so it's a lot of investment from the families. They've got someone there for three hours shadowing them almost for several weeks really and this is something I always explain to them when I go out and do the assessment, you might initially question if it is worth the bother but it's trying to reassure them that in the long term "Yes it is" – it's going to give them a lot more freedom.....having given this investment it is very difficult to then have to tell families that we have no service to offer because of sickness.

The same issue also arises during staff holidays. One worker being on holiday in a two worker service can have significant implications for service delivery. The original budgets did not include monies to backfill posts during holiday and sickness

How viable are small services? At a recent Operational Group (February 2005) the following observation was made:

[resources] will have to come from fairly high up from the strategic health authority I think really more than locally because there is not a big enough number of children wherever you look really if you are being purist about it that have palliative care needs... so it is a bit about joining together maybe in the future so that we have more of a regional service that can offer a service to forty children as opposed to one service offering for ten, another offering for ten, and so forth.

The parents' / carers' views of this can be seen in Section 9.

### ***Supervision of the BLF workers***

All of the service managers view staff supervision as a vital part of their job. They recognise the responsibilities carried by the BLF workers, how this differs from that carried by family members and the cumulative emotional and physical effects of working with children with life limiting conditions. This should be placed within the context of BLF workers at times working on their own away from their base without ready access to support.

One Service Manager summarises many of the relevant issues.

I think staffing is one of the biggest issues and I feel staff are supported quite well, I don't know if other staff feel that way. I do think there is a certain degree of – I don't know if we are going to get burnout with them – you are

actually working with these children. As a children's community nursing team we deal with a lot of children with complex health care needs – we sometimes have runs of children who die and I think we've got quite good peer support in the office. I worry that when you are working with these children the general carers might not get the same level of support but having said that, the one child who we've had who died the child health carer is linked with a member of the team and has got the support that she needed. That was one of the reasons we tried to put people in pairs – I think when you are on your own it is scary stuff even as a qualified nurse. Some of these kids are scary. We talk about it and say well the families do these things – we're not asking anyone to do any more than the families do but when you are actually looking after your own child and then you are asking someone else who isn't a qualified nurse to care for the child there's a big difference here – although they are doing the same as members of the family ..there's a different responsibility somehow ...

One way of supporting BLF workers has been to

... give each carer a mentor within the community children's nursing team because all of these children are known to us – they've been known to us some of them for years and years and years so we've tried to set up a system whereby they have a link person because the children don't have named nurses as such but they've got someone who links in probably more with the families than with anyone else so there are people who always take the lead in children and almost every family will choose their lead – they will say can I talk to so and so.

### ***Training of the BLF workers***

In general the training pattern has been:

- An initial introduction and general training relating to BLF work.
- The general training has, in some instances, also involved practical placements with, for example, CCN's.
- Specific training around the needs of specific children / young people as part of being introduced to them and their families.
- Issue based training (e.g. handling bereavement).

Specific issues arise when taking on new staff (not a big enough group to provide the original general training) and members of staff who are taken on in specific geographic locations for specific service users. Training is also affected by the hours that staff are recruited to work.

Well, I found it worked quite well because the problem then, if you employ staff on shorter hours, is the training issues. Having most of the staff and the one on 16 hours during their training – the main part of their training is 3 weeks where we did classroom based training actually went up to full time to facilitate that and the problem if you just employ someone for 7.5 hours a week it could potentially take months and months to get them trained. But then you want the flexibility so it hasn't been easy. Luckily the girl who works up in "Z" – I've gone up and done some specific training around that

particular child that she is linked in with and left it at that but with the rest of the staff I wanted to try to give them quite a global training so that they could potentially link into any child and then when they were allocated their caseload we would do more child specific training with them. So it has certainly thrown up its challenges around the training.

Training has also been needed around specific procedures / equipment.

Specific training they've needed really has been around specific feeding pumps or emergency medication if a child has got epilepsy and they are going to need something specific to that child at the time. It's just really if a child has a specific piece of equipment – they need training in how to use that specific piece of equipment.

Who has given this training?

In some instances it has been the Service Manager in others it has been the CCN or another professional involved with the family (e.g. Physiotherapist)

Because all of the training is done on an individual basis. I couldn't take you outside now and train you to do a suction tracheotomy which would then mean you could go and do that to anybody. You have to be trained on every individual child so that puts a lot of pressure on the nursing teams as well because they are very busy people and it takes time out of the teams to do training.

Training in bereavement and loss has been provided in response to BLF workers' requests.

We had one bereavement just at the end of this week which was quite unexpected and hit the team quite hard.

Bereavement and loss is an issue of particular relevance to this group of workers.

This issue is also addressed by workers from Barnardo's Orchard (Serious Illness) Team attending team meetings to offer team support.

They also meet on a monthly basis with the co-ordinator and with the clinical lead from the team and the Barnardo's worker and any ongoing training issues are dealt with by the children's community nurses and the co-ordinator.

And...

What T (the Barnardo's worker) does is he does 1:1 with us. I wouldn't say it's clinical supervision but we sit down and talk about what's going on with all our families and all sorts can be covered in that and he can put on a completely different perspective on things.

More details of training can be seen in *Section 8: Description of the Services provided through BLF programme.*

### ***Families not being in when the BLF workers calls or cancelling at short notice***

A particular issue that has needed to be addressed is that of families not being at home when the BLF workers visit.

We are limiting the service – they only get one period a week these children and from then three of the service users have left the service – not so much left it but the BLF workers were arriving and weren't needed so I had to address that quite sensitively because that was the fourth and fifth time and these girls could be giving that service to other families who need it. It was a waste of a resource.

Another Service Manager comments:

I have had no negative feedback at all apart from, and it wasn't negative feedback, when the person kept refusing the service – well not refusing the service but they were saying 'oh, he's had a bad night we aren't sending him to school today' and that happened five or six times. It wasn't that they were negative about the service – they loved the service but they had to be told that we couldn't keep coming and landing on the doorstep to be told "No". But I have given them the opportunity to ring me when they do want it back, if they want it back.

Another comment has been:

That's one of the things that is a down turn and I think I have asked this at the Operational Group meetings is when families cancel. We haven't got so much of that now but we had a few families who were not very reliable and would ring up at short notice and say "Oh I'm going out I don't need the worker". And then trying to find somewhere for the worker to go at very short notice was very difficult and I often had to "board them out" with the nursing teams. The staff weren't happy with that I must admit because that wasn't what they wanted to do.

### ***Access to residential care***

In one area the BLF workers have been used to facilitate access for service users to existing residential care units. This has facilitated both access to these units (and thus short breaks that would otherwise not be available) and also access to social activities for the young person when they are in the units.

They were already known to the Children's Community Nurse and basically they weren't getting any respite service previous to this service and that's how the bid came about really. We found that there was a lot of these children whose families desperately needed respite because of very severe disabilities but because the main problem was that they were gastrostomy fed they couldn't access the overnight residential facilities. ... Now we managed to get them all in on the same weekend once a month and we have one child who accesses it one Monday every fortnight because his mum feels having a Friday, Saturday and Sunday night is too much for him so he has a Friday and

Saturday night goes home on the Sunday and then accesses it two weeks later on a Monday and that is at her request. So basically what I do is to put two staff members in that weekend – it doesn't just mean they are linking in to do the feeds for the children what was also happening was that the rest of the children would be going out for the afternoon, for the morning, for the day – it's not just our children there – but our children weren't able to do that because they had to wait around for the nurse to come to do their feeds. Now they can go off because the nurse will just go with them. So it has aided a lot of social activities for them as well ...

Such support also enables families to plan to go off on holidays.

So a lot of these families who have never been able to go away on holiday with the other siblings as a family are now able to do that for the very first time.

### ***Hours worked / week-end cover***

At what times / occasions have the heaviest demands been made on the services?

... our workers are much busier during the school holidays and there tends to be completely full diaries at that time and we probably wouldn't be able to fit in everyone in one week.

And

Most of it has been first thing in the morning like the school run say 8.30 – 10.30 time and some after school say 15.30.

Another manager comments:

We try and stick to 8 in the morning to 8 at night but if it was an end of life situation we would put a 24 hour service in. The only way to potentially facilitate that would be that we might have to pull back the routine respite for other families to cover that but at the end of the day my priority would be for a palliative child.

A further work pattern is:

In the introduction period they were basically doing 9.00 – 5.00 Monday to Friday we don't offer a weekend service yet and I don't know if that will come off but I would hope to see that we could maybe offer a weekend service and we would offer a weekend service if there was an imminent death and there is provision for us to be paid for that, myself as well, so the CCN and the nursery nurses would go in and do that weekend service if it became necessary. We don't offer it at the minute.

### ***The BLF service as an alternative to hospital admission and other services***

One outcome of the services appears to be the reduction in demand for inpatient care – i.e. in some instances the service is preventing hospital admissions.

That's one thing I think apart from the medication there was no cost implications apart from our costs – mine and the nursery nurse's but compared to a bed on a ward for two days and nights on a ward – these are very expensive, special care baby units – high dependency units.

I even think the nursery nurses going out to the other families – I'm just taking one little girl as an example, they were in hospital quite a bit but I think just because they are seeing that nursery nurse and they can chat that child hasn't been in. So we have prevented some admissions. They've obviously been poorly and the CCN goes out to see how well they are, does investigations and things like that and obviously if they are poorly they will be admitted but from the point of view that they haven't been poorly when they've come into hospital it's just been that mum was chewed and worried I think just having that relationship with the nursery nurse who might not be experienced to say "Oh no she doesn't look well", but can just talk to her and offer to change the child, reposition her, get some secretions out.

One manager comments:

I don't think there would be such a flexible alternative because we just try to fit in completely with when they need us and we don't set it in stone, we don't say well we can only do .... we just agree it with them, the time when they need it. The alternative might be things like sponsored childminding and Sure Start nursery places if you can get them – they are often full and they are for set days and set times and it would be outside the home, whereas a lot of what we are doing is inside the home.

Choice can depend on how alternatives are perceived and what choices are seen as available.

I guess some of the ideas around "I perhaps wouldn't want my child to die at home" might be based on what your perceptions are of current services. If you felt you were going to be on your own doing this then that might be very daunting. But if you know there is support there then obviously your ideas might change and you might exercise your choice differently. So you are absolutely right, it's only when people see what might be possible that the ideas might change and other choices become a reality. We've introduced that choice which wasn't there before.

How does the BLF service compare with previous service provision? One service manager describes the difference thus:

As a CCN you would go into the house of a child that would fit the criteria here - I would usually put that it was home support - and you would just talk about the situation but you would only be there about half an hour and even if you were doing something physical you might only be there half an hour whereas a support worker goes in and is there to feed the child if it needs feeding, change the child if necessary but I suppose in some respects what I get back from the support worker is that they talk to the parent as well so they build up relationships with the parents – they've got more time to spend

there and can listen to parents talking to them in a way that as a CCN you haven't got time to.

### ***Introduction and flexibility of service***

Flexibility is aimed for in a number of ways. One is to allow BLF workers to organise their own rota to fit in with service users' needs and their own commitments (e.g. holidays etc). Thus once the service has been negotiated with the family the BLF workers are given the freedom to then negotiate the details with the service users. Thus:

Usually I would do a joint visit with either the nursery nurse or the link worker to introduce them at the same time to talk about what they need and what they are hoping to get from the service and then talk about what we can realistically provide – it might be a couple of sessions a week or one session a week but it's all quite negotiable – the 'A' grade and the nursery nurse keep their own diaries and they will fit the families in depending on what the families request and what they can manage and I'm not in any way dictating to them that 'you must go to see this family at this time.

The degree of flexibility can be affected by a number of factors. Whilst one service manager comments:

We're really flexible to be honest – whatever the family want that particular evening. Sometimes a couple of hours to go and get the shopping whatever but mostly it's about three hours a couple of times a week.

A second Service Manager comments:

Our families are asking for specific afternoons quite a few of them and it is getting quite difficult because there are so many of them wanting a certain time on say a Tuesday and then there are the ones who don't request anything specific and they just get what is left.

### ***Time limited or open ended service?***

The different areas have different policies regarding how long the service can be provided. For some there is no limit, for others the limit is three months. In some areas no transfers have happened so far. At a recent Operational Group (February 2005) it was noted that in the case of one family the child had died waiting to be transferred (the referral to SSD had been made the previous November). The discussion that followed included the following views:

The only problem is obviously we had to refer after three months to social services and at the beginning it hadn't worked so I did the first one in November and social services were still looking into it last week so that's nearly three months and the child has died yesterday.

One member suggested:

I think one of the problems is that the services are doing things that have never been provided before and so social services with the best will in the world haven't got the resources or the inclination or the skills really. There is nowhere to turn and this is really why the service exists because it was an identified gap.

The importance of the relationship between service and families was also highlighted:

Also some of our families who have had the BLF workers in will just not accept social services so what do you do? Do you pull out and not give them anything? We haven't, we've just kept going but about four families just said no we won't have anyone else. They've built up that relationship with the nursery nurses – trusting them, letting them go out now, they do go out and that is going to be very difficult. So what I am trying to do now with the new ones is to stipulate that after three months – I'm saying three months but it won't be because it will take six months to get someone. Social services haven't got anyone who can undertake tracheotomy care or have the same skills as the nursery nurses. So that is quite frustrating at the minute.

Concerns were expressed about the priority that Social Services give to this group of service users:

The problem is that social services have very different priorities. They are very driven by child protection. A child in need, and maybe these children fall into that category, is not a priority. They would like it to be, if you speak to any individual practitioner they would say yes they are but in the reality of the world they have finite resources and they have the priorities they have to work to. And they haven't got the resource, as in people, to put in. I can speak from area X point of view there isn't any provision within area X that could do the same sort of thing that the BLF workers do.

For some there is a real issue of being time limited but there also being no agreement with the area, to whom the service user should be transferred, to provide a service.

.....we run into a problem when we work in [Area Z]. This area never bought into the service at the outset so I come into problems there because there are children who fit the criteria.....it was agreed that after three to six months that social services would then take over if it was at a point where we would start to build relationships up with their link workers and they would then move in to the families and we would pull out. I can't do that in area Z.

There could also be benefits in the service being time limited to avoid dependency developing:

I think it would depend on the child but I think the aim has to be that people aren't too dependent on one person and that they have some sort of quality of life and obviously if we've got babies, as the babies are getting older they

need to have social interaction with other children which we can't necessarily provide them with just by going into the house to look after them and if we can't persuade the mother to use the time to go to things like soft play and mother and toddler then we need to be referring them on to nurseries and places like that where the child will get social interaction as well and that's where it would have come in useful to be able to say we set this out as a three month thing to assess your needs and we've assessed your needs and think you need to look at a nursery placement.

For some families coming to accept the BLF service has been a major achievement and having worked hard at gaining trust and being accepted the challenge of even discussing transfer is very great. The different perceptions of health and social services provision is also an important factor here:

Some families you can think they will be alright, some families I know will just not have a service (from SSD) – they'll refuse it now because we've worked so hard to get them to have the service that we've offered and then for us to say right we are going to be introducing someone new, who will be trained exactly as the nursery nurses are, but ...

I think they would offer the same kind of service in the way that they would be able to because they would have the appropriate training but I just think the mums won't want to build up that relationship and you know what it comes down to, we've been nurses and I think they must think we are from the hospital and these mums have never wanted a social worker so they won't want a link worker from social services.

I know from the original bid and now looking back on the last year I would have liked all of the funding to have come ... because some of it went to social services and they obviously have to provide a service because they've signed up to it but I do think we could have had two or three extra nursery nurses and avoided the issues around transfer ...

This is also linked to clarifying expectations about time limits from the outset:

There are challenges around different expectations, I think we probably didn't explain things to families as well as we could have done at the very beginning as to what service we could provide and there was probably a difference in expectations.

The issue of transferring families to Social Services has also been discussed in depth at a recent Operational Group and is causing some concern amongst the group.

It's very much where you see your service going and I think some of the feedback from what you were saying about stopping after three months that's not awfully fair for families because that's almost setting them up, seeing what it is like to have support and someone to help out and then to be told, "Whoops here we go - end of the service", just when they had got into it. And in three months, in practice, the workers are just getting to know the families, they are just getting to the point where the families feel that they can trust the workers enough to leave them and go out and do the things that we had hoped they would do in the first week.

It's like setting them up for a fall because that's very much how the families we have helped and pulled out from feel – they think “Although it was a great and beneficial service we wish we had never had it in the first place because it has just shown us how much we are missing out on.” They could see their children coming on because they were getting this 1:1 input.

This, in turn, has been linked to the challenge of being accepted by families in the first place. A member of the group has commented:

What I hadn't anticipated was the hard sell we had to do with families in the first instance. I knew that has been a problem around persuading families to accept respite in residential care such as St Oswald's or whatever it is in the city. I can appreciate that because I would be pretty wary as well. But even to get someone to come and help in their own house.....this can be very difficult and needs persistence ...

This issue was also remarked on by service users (See section 9).

### ***How do the Service Managers see the future of the service?***

One manager comments:

I think really it's like building blocks – it's carrying on building on what we've already established. No major changes, just continuing to develop as we go on.

Two other managers offer contrasting views depending on the nature of their funding and contractual status.

Yes, it is intended that the BLF service will continue beyond the three year period.

As far as I know the PCT agreed exit funding right at the beginning before I was ever even in post. My job was advertised as a substantive post and to the best of my knowledge the idea is that we keep on providing the service and in fact hopefully increase the amount of time we've got.

In contrast to this...

Whereas area H hasn't committed itself to funding past the three years by only looking at the three year period for employment. This makes it difficult to plan ahead.

## **Summary**

This section has outlined the issues that have arisen from the various perspectives of the Service Managers during the implementation stage of the BLF services.

In particular the section has outlined issues relevant to:

- Why were these services developed – views of the rational(s) for the development of the BLF services.
- Details of who the Service Managers are and how their backgrounds and various roles impact on service deliver.
- The Recruitment / Retention of BLF Workers.
- Referral /Assessment processes.
- The impact of staff Sickness / Holiday on service delivery.
- The supervision of the BLF workers.
- The training of the BLF workers.
- Access to residential care.
- Hours worked / week-end cover.
- The BLF service as an alternative to hospital admission and other services.
- The issue of services being time limited or open ended.
- How the Service Managers see the future of the service.

## Section 8: Numbers of children / young people receiving the services.

In February 2005 a Monitoring Form, devised through the Audit Sub-group, was completed by each Service Manager (see Appendix 2).

The data in this section is taken from the Monitoring Form and shows the number of service users using the service across all services up to and including 28<sup>th</sup> February 2005.

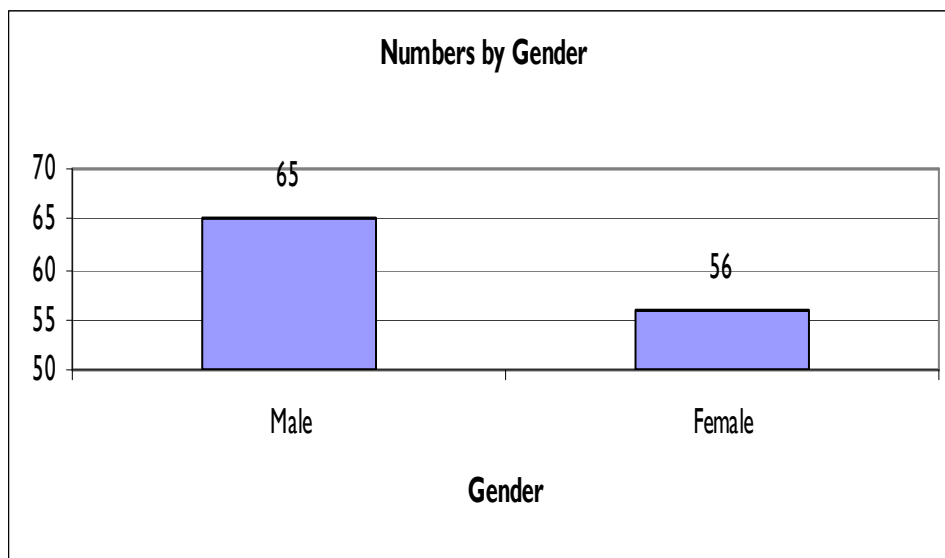
It should be noted that services started at different times and thus the time period will be different for each.

The figures below, however, give useful indicators of service use.

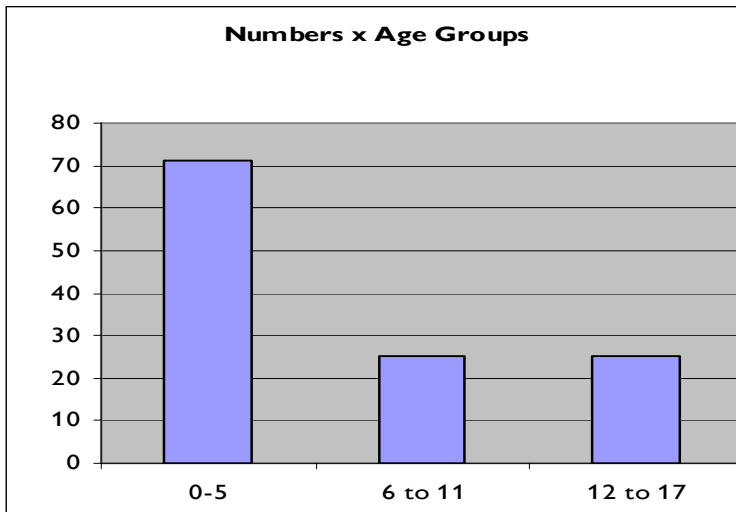
The total number of service users supported up to 28<sup>th</sup> February 2005 is **121**.

These can be broken down as follows:

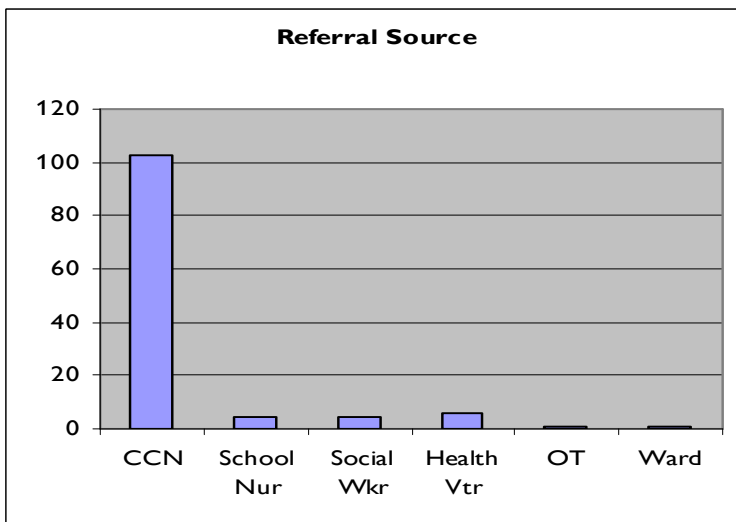
### Gender of young person



### Age of young person

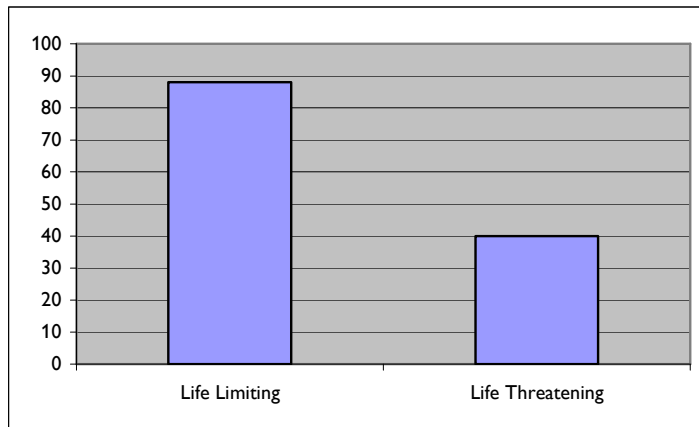


### Source of Referral



**The number of deaths during this period has been: 5**

## The Nature of the referral



## Referral Status

Referral Status	
Total accepted – service allocated	65
Total accepted – service not yet allocated	18
Total declined by service – do not meet criteria	2
Total declined by service user	21
Closed	34
Awaiting Transfer to SSD	4
Transferred to SSD	4

## **Section 9: Description of the services provided through the BLF programme**

The data sources for this section are:

- The minutes of a workshop for BLF workers held November 2004.
- The BLF Monitoring Form (see Appendix2).

The BLF workers are the key means by which the service is delivered. This section gives an overview of the range of activities that they have undertaken with service users.

### **Data from the BLF workers' workshop held November 2004**

In November 2004 a Workshop for the BLF workers was organised by the Operational Group. The aims of the workshop were to:

- Celebrate the work to date.
- Enable the various areas to share experiences of their work.
- Identify the benefits / challenges of the work.
- Identify future training / support needs.

A wealth of rich information came out of this workshop. This is summarised below.

### **Summary of key Issues identified by the BLF workers**

- The impact on small staff groups of holiday and sickness – difficult to keep up quality of service during these times.
- The challenge of negotiating boundaries – “for the service to work we need to be informal and almost like a member of the family – but we recognise the need not to encourage dependency - not sure where the boundaries are in these situations.”
- Families open up to the carers more because they are with them longer – uncover needs that parents might not raise with CCN on their own. Parents so grateful for help they often don't want to ask for even more.
- BLF workers have been able to introduce services that families either did not know about or were reluctant to accept previously.
- Where it has not been possible to transfer families to SSD then some families who should be passed on will be re-referred to keep them in the service.
- Recruitment and retention of staff have proved problematic in some areas.
- A whole range of benefits were identified for the parents/carers / the child / the siblings.
- Boundaries around working with siblings have had to be negotiated at times (where families have requested, for example, that the BLF worker looks after a sibling as well as the referred young person to allow parents to go out and socialise).
- Workers need to really work at gaining trust and being accepted by the families to be effective - breaking down barriers. It can take a long time sometimes for parents to trust worker with their child – one worker was

several weeks into visiting and mum still will not leave her alone with the child.

- All BLF workers reported high satisfaction with the job, whilst recognising how challenging it also is.
- Families often need the service before and after school – difficult therefore to cover all the referrals – staff occasionally have had to do split shifts – generally not happening now (i.e. demand clusters around specific times).
- BLF workers support other professions and extend this provision (e.g. workers undertaking tasks on behalf of OT, Physiotherapist, Speech and language therapists as well as CCN).

More particularly the following was discussed:

### **Challenges**

- Staff sickness – with small staff groups – pressure placed on the remaining staff and on the service to existing clients. Little account was taken of backfill budget.
- Some service users become over dependent on one worker to the extent they are reluctant to have another worker in during holidays / sick etc. Need to develop team approach so families get to know a small group of workers (where this is possible).
- Building up a relationship and then having to withdraw the service either at closure or on transfer. In such circumstances disengagement can be stressful.
- Lack of clarity about who will step in after three months (in those areas where there the support is time limited).
- Some families who should be passed on will be re-referred to keep them in the service.
- Need to address safety issues for lone workers (safety, risk etc).
- Recruitment of staff has proved problematic in some areas.
- Maximising the flexibility of the service to enable it to meet the changing needs of families.
- Workers “take work home” with them – thoughts about family – very emotional work.
- Problem of last minute cancellations by families – how to fill time.
- Importance of knowing one’s own limits - “we try to but can’t do everything”.
- The service is declined by some families – not ready to accept a service.
- Socialising of children by taking them out – issue of using cars – where cars can be used then easier to take out younger children than older children. In some areas staff cannot transport in their own cars.
- Different standards at times – the gold standard as taught by nursing staff vs. actual standard possible within individual homes (e.g. levels of hygiene). Workers have to follow rules whereas families can take short cuts. e.g. wearing gloves.
- Workers juggling the expectations of families with the “professional” boundaries of the service.
- Boundaries around working with siblings have had to be negotiated at times (where families have requested, for example, that the BLF worker looks after a sibling as well as the referred young person to allow parents to go out and socialise).

- Feelings of responsibility of working alone.
- Over time families want more as they experience the benefits of the service.
- The service has a natural limit due to the limitations of resources.
- No smoking policy – some families smoke – “health hazard” for workers.
- Workers helping to negotiate language barriers when supporting non-English speaking families.
- Emotional links develop between the worker and the children and families.
- How to retain appropriate professional relationship when in regular contact and nature of work.
- Family reliance – the worker can come to be seen as a mother/daughter figure.
- Boundaries around companionship.
- Workers need to really work at gaining trust and being accepted by the families to be effective - breaking down barriers. It can take a long time sometimes for parents to trust worker with their child – one worker was several weeks into visiting and mum still will not leave her alone with the child.
- Need to overcome family defensiveness (inference of not coping).
- Mobile phones used a lot to support each other.
- Expectations of families and professionals.
- Emotional support (knowing own limits).
- Need to recognise own competencies and seek out advice / training when needed).
- Parents sometimes ask the worker questions that they have to be careful when they answer as the parents may distort the response and recount it to others or take answers as definite advice when really it was possible ways of doing something.
- Difficult if after 12 weeks there is no service provision to take over especially those with medical needs as they have no one to take over. Difficult when there are competing demands – new families that need help coming onto the books.
- Some parents may see worker as support for them primarily and want to chat to them (perhaps not had many opportunities for socialising) and carer might be keen to take the child out of the house and give them experiences outside.
- In end of life situations workers have been encouraged to continue to have some contact with families both for their own benefit and that of the family.
- Over familiarity can be problematic – swearing in the home in front of the workers.
- Children mostly wheelchair bound – difficulty transporting them on outings (mainly funded by parents).
- Workers feeling that the family are dependant on them as individuals - may even impinge on when they take their holidays.
- Fine line between getting involved and being in too deep.
- In some families there has been a need to put two workers in to the home for personal safety.
- Difficult to exchange carers – parents often compare to first carer as this is their benchmark – just having one person can cause dependency.
- Cancellations not a big problem usually because the family have someone coming to visit, one family just wanted some time alone with new baby without others in the house.

- Families often need the service before and after school – difficult therefore to cover all the referrals – staff occasionally have had to do split shifts – generally not happening now. Some areas do annualised hours.

### **Benefits of the Service**

- Visited and supported children in hospital / and Social Services short break provision.
- Benefits children being taken out and about – when would not otherwise be possible – workers also able to take all necessary equipment.
- Benefits to family – parents catching up with sleep, going shopping without wheel chair, getting time with siblings.
- BLF workers not seen as professionals – families gain greater confidence in, and more open with, BLF workers.
- Currently no uniforms used - to minimise formality.
- Parents going out together for the first time in two years.
- Privileged to go in – get a real “feel good factor”.
- Become part of the family.
- Have followed children onto ward when admission has become necessary to assist and advise nurses.
- Enables parents to have a chance to spend quality time together – relief to parents.
- Flexibility for children/families – some staff work over 24/7 (although there are differences in the different areas around what days / time periods are covered.
- Become part of the family – seen as friend rather than professional.
- BLF workers sign posting to other services – helping to negotiate involvement of other services. Building trusting relationship with family to encourage families to access services they had previously been wary of accessing.
- Age of worker – one worker being seen as parent figure where young mum had lost her own mother.
- Some of trust given by families comes from workers being employed by health – perceived credibility in dealing with health related issues.
- Language barriers – one family – mother French / father German – BLF worker acting as “interpreter” – helping family negotiate with agencies.
- BLF service supports other professions and extends this provision (e.g. workers undertaking tasks on behalf of OT, Physio, Speech and language therapists).
- Flexible/non-formal/friendly relationship.
- Feel as though doing something good so close relationship can be very positive too! Able to give benefits to both children and family and draw on other services plus trust families have supports this.
- Enjoyable work – “feel good factor”.
- Workers feel well supported.
- Chance for parents to go out/sleep.
- Support to families in communicating with other professionals e.g. contact with medics.
- Families can offload their feelings to workers.
- In the main the services try to offer continuity for families – same worker – to enable effective working relationships to build up.

- Families find it easier at times to question the worker rather than the nursing team.
- Rota – ‘know where you are at’.
- BLF workers bring different skills and experience to the work which complements that of the other professionals.
- Enables families to do ordinary things – sleep, shopping etc. Enables children to participate in ordinary activities (which they wouldn’t be able to without support).
- Easier for families to accept BLF service (not so formal/professionalised).
- Workers gain skills that they are able to use in a variety of situations.
- Ability to carry out a range of different tasks – support and guidance until BLF worker confident.
- Families say they want more of it and longer.
- Families are very grateful even though (for one care worker) it can be short term help.
- Sometimes workers are advocating for the families to the CCN (e.g. they might ask the CCN to re-assess if they realise that the family still need more help).
- Families open up to the carers more because they are with them longer – uncover needs that parents might not raise with CCN on their own. Parents so grateful for help they often don’t want to ask for even more. (One worker described a situation where a mum had three children, two of them were autistic plus a baby with Down’s syndrome – in between feeding the baby she was up most of the night as usually one child would awake and not want to go back to bed and this would wake the other child up. The worker could see the mounting problems and physical exhaustion and asked for more help for the mum.)
- Service gives parents more freedom.
- Some parents may not like doing some of the tasks e.g. changing the tracheotomy tube on their baby so they will ask the worker to do this – gives them some relief from this job.
- Relief/respite (from isolation).
- Comfort/support.
- Socialisation – the worker may be the only other adult the parent sees through the day.
- Information/advice.
- Workers suggest new opportunities to the parents.
- Siblings enjoying ‘a fresh face’.
- Enables parents to get out of house.
- Extra pair of eyes and ears in home for longer period of time – parents too frightened to ask.
- Giving carers time for themselves, partners, siblings (gratitude!! – want more!).
- Support – someone to talk to – increases choice/gives freedom.
- Advocate for carers – worker can speak up for them.

### **Benefits to child**

Many of these benefits are included in the points listed above. Further benefits include:

- Increased opportunities that child did not previously have.
- Continuity of care in other settings (e.g. Social Services short break care, hospital settings).
- Child has one to one support.
- Workers able to progress developmental programmes i.e. physio / SALT / Portage agreed with other professionals.

### **Benefits to siblings**

- Parents have more time for them.

### **Benefits to BLF workers**

- Workers love the job they do.
- They saw the relief on parents faces when they came in.
- They felt really appreciated by the families.
- The children's responses to them were rewarding – some would crawl to towards you as they heard your voice.
- Some workers were finding that they could offer the child increased opportunities that previously weren't manageable for the families e.g. trip to Centre for Life and sensory rooms.
- Workers have gone into hospital when child has become ill –relieved parents or supported them.
- Professional/personal development.
- Positive feedback from families.
- Training/skills/support.
- Building relationships.
- Experience of placements.
- Reduced calls to CCN team.
- Enjoyable/rewarding job.

### **Training and support needs**

- Availability of CCN advice – on-call CCNs advice re medication a frequent issue.
- Communication between parents and short break care units a key issue
- Monthly team meetings.
- Monthly clinical supervision.
- Weekly/daily communication between team members – formally and informally.
- Need for additional support when offering end of life care – need for debriefing opportunities when not office based.
- Workers sharpening skills with each other.
- Three week intensive training package – basic childcare to complex medical procedures including child protection training.
- Need to refresh training regularly - child protection, moving and handling etc.
- Training provided to a small group (5 members) which developed good team working.
- General and individual training provided.
- Challenge of training new workers when numbers too small to put on a group training programme.

- NVQs to be available in future - ?career progression opportunities.
- Training as issues arise.
- Advice about helping parents through the grieving process.
- Supportive environment using all resources available.
- Communicating with non-verbal children.
- Therapeutic play.
- Information about local/national services available to families.
- Visiting/experience with the services.
- Palliative care – symptom control etc.
- Children with visual impairment.
- Time management.
- “It’s only when you’re out there that you learn”.
- “A lot of our training is undertaken by the parents”.

### **Training priorities**

The following training opportunities were identified:

1. Therapeutic play, communication skills, play skills.
2. Working with children who are disabled visually.
3. Dealing with bereavement – for both family and worker.
4. Basic counselling skills (e.g. listening, responding etc).
5. Dealing with boundary issues.
6. Palliative care skills.

This data will be complemented by further in depth interviews with BLF workers to be carried out post April 2005.

### **Quantitative data**

In February 2005 a Monitoring Form, devised through the BLF Audit Sub-group, was completed by each Service Co-ordinator (see Appendix 2).

This form gathered data which illustrates the range of tasks undertaken by the BLF workers.

Table 9.1 shows the primary activities undertaken by the BLF workers. Each activity is the number of times that activity has been undertaken out of the total of 121 service users.

This table demonstrates the range of activities carried out by the BLF workers which include medical interventions, activities on behalf of a range of professionals and a range of social activities addressing the social / emotional needs of service users and their families.

**Table 9.1 BLF worker activities**

<b>The instances of each activity being undertaken for the 121 service users</b>	
<b>Activity</b>	<b>Numbers</b>
Tracheotomy	10
Gastrostomy	40
Naso-gastric tube	25
Ileostomy	1
Colostomy	1
Hoist and wheelchair	5
I/V factor 8	1
VP shunt	1
CPAP	1
Ventilated	1
Pulse oximetry	3
Administer oxygen	2
Suctioning	1
Work on behalf of CCN	26
Work on behalf of OT	5
Work on behalf of Physiotherapist	25
Work on behalf of Speech and Language Therapist	14
Massage	6
Portage	6
To offer emotional support to parents/carers	72
To enable parent / carer to go to work	20
To allow free time for parents/carers	55
To allow parents/carers to spend time with siblings	27
To facilitate socialisation of young person	31
Facilitating access to other services	33
Meeting the learning and development needs and stimulation of the child	60
Direct work with siblings	4
Other (Oxygen dependent)	7

The Regional Questionnaire for all of the BLF services is also being analysed and this will be available post April 2005. At this time there are 34 completed and returned questionnaires. Not all respondents completed all of the sections.

One question is worthy of note at this stage. It asks parents / carers if they think that the BLF service has reduced:

- demands on their GP
- hospital admissions
- demands on the CCN team

The responses were as follows:

Q: Would you consider that this service has helped?

	<b>Yes</b>	<b>No</b>	<b>Unsure</b>
Prevent hospital admissions	10 (29%)	16	5
Reduced visits to GP	11 (32%)	15	2
Contact with the CCN Team	15 (44%)	9	7

These figures, albeit from a limited sample (34/121), suggest the savings that might accrue to other services that might normally have been demanded by this group of service users. This might be worthy of more detailed research.

## **Summary**

All of the above data suggests that BLF services:

- Could be linked to a reduction in demand for other more expensive services.
- Are substituting for and extending existing community services.
- Are providing a wide range of medical and social services to service users.
- Occupy a unique position at the interface between formal and informal service delivery that brings with it both benefits and challenges to workers and service users.

## Section 10: Analysis of the difference made to children’s and their families’ lives

This section details the impact of the BLF services on families from a number of perspectives namely:

- Parents / carers
- Service Managers
- BLF workers
- A range of professionals

It should be noted that it has not been possible at this stage to obtain feedback directly from children and young people. Skills, resources available and the lack of verbal communication of many of the children and young people receiving the service have affected this. The communication methods of a sample of children and young people were explored to provide information that would help future research in this area which should aim to obtain feedback direct from the young people. Table 10.1 gives examples of the communication methods of this group of young people.

**Table 10.1. The communication methods of a sample of children and young people supported by the BLF services**

<b>Age</b>	<b>How does the young person communicate when they are enjoying an activity</b>	<b>How does the young person communicate when they are not enjoying an activity</b>	<b>How does the young person communicate when they are uncomfortable</b>
4	Asleep, relaxed	Wriggles,	Wriggles,
14	Maintain eye contact, relaxed, smiles	Squeals, out stretch movements	Cries
3	Laughs, holds hand, Makaton	Throws things	Holds the part of their body that is hurting
15	Very relaxed, gurgles	Cries, makes noises	Very restless
8	Laughs, smiles, makes noises	No smiles, may shut eyes	Very quiet, no communication
3	Laughs, smiles, vocal noises, claps, Makaton	Will not be interested	Facial expression
13	Lifts hands into air , smiles	Hand on chin, very solemn face, looks away	Cry, unsettled, sweaty if in pain

Through discussion with the Operational Group it was agreed that the sample chosen was representative of the whole group of young people receiving the BLF service.

The ability to recognise and understand the unique non-verbal communications of a range of children and young people has implications for skill development and methodology in both practice and research in this field.

## **Parents' / Carers' perception of the impact of the service**

### **Data sources**

Qualitative data was collated via both interviews with parents/carers and comments made by parents/carers on their postal questionnaires.

Interviews by telephone represent a sample of parents/carers (10) who gave permission to be "further consulted" when completing the regional postal questionnaire.

Telephone interviews were the method of choice as families' lives could be unpredictable given the nature of the challenges facing them. Telephone interviews could be conducted at times that suited parents/carers, rearranged at short notice and curtailed if parents needed to attend to their children.

All of the telephone interviews were conducted with female parents/carers.

As well as producing quantitative data, the Regional Postal Questionnaire also invited parents/carers to make any comments they thought relevant. These comments are also included below.

### ***Impact on parents / carers***

The following quotations are representative of the feedback from parents / carers. It represents a cross section of benefits perceived by parents / carers. These comments have been derived either from telephone interviews by Barnardo's Research and Development Team or from anonymous Regional Questionnaires.

The main areas of benefit include:

- Time to be with partner.

"I get 2 hours per week. This allows me to have uninterrupted time with my partner."

It has given us the opportunity to do other things and I feel comfortable leaving my child with the support workers"

- Relieving some of the stress in the relationship with the child.

"Just to say how grateful we are as a family (of 5) – this has been the only respite of D that we've had and it's been excellent – wish there was more for longer."

"It really helped J – he stopped being so clingy to me. So I got some rest too!"

"It gives us more time for other members of my family. The whole family unit benefit. As the service assists us to cope, our child benefits greatly by having less stressed, kinder carers."

- The opportunity to spend more time with a sibling.

“It gives us the opportunity to spend time with our other child or do things I would otherwise find difficult.”

“It was lovely for me and my other daughter to get out for a day or two during each week of the school holiday – It would have been nice if we could have got A out as well.”

- Relieving isolation of parents/carers.

“This service is very useful during school holidays for me as I am completely isolated during these times and am unable to go out or do anything for A as she requires two people for transfer. Therefore when carers come in it relieves me from time to time.”

- Increasing the range of activities that the child is involved in.

“J has been taken out on trips he would not normally have been on. I have been able to go too.”

### ***Parents’ / carers’ perceptions of the impact on the young person***

Parents have commented on the opportunities for increased participation in leisure and recreational activities and enhanced physiotherapy input.

“It is good for Y. to be with other people rather than myself all the time.”

“Giving one to one attention and stimulation has had a great affect on him.”

“The physiotherapy given by the (BLF) worker has benefited him and he has enjoyed going out with the worker.”

“K is thoroughly spoilt with much more one to one attention than at home where she is part of a family of 9 ( if you include the animals) all of whom require attention.” (with reference to short break care).

“He received physio from home care worker during the school holidays this was a big help.”

“He looks forward to different company, stimulation and activities provided.”

The workers provide my child with outings, play, games, everything I would do for my child.”

“My child is more sociable and is making progress in all areas due to input from many people.”

“The service has provided transport for my child’s own recreational time.”

“She loves the play activities.”

### ***Parents’/ carers’ perceptions of impact on siblings***

“My older child benefits by allowing us more time to be together.”

“It allows brothers / sisters to undertake activities which they cannot do with M around.”

“Enables my 3 year old to go places she might not normally go (e.g. McDonald’s).”

“They also take the 5 year old out during school holidays – it helps the two daughters to be together.”

“We have more time with D to sit and watch TV with him, pack his lunch, and help with homework.”

“When D got his care it meant I could spend some time with my daughter and do what she wanted which was lovely.”

“We have a block of guaranteed time when we can do this rather than snatching small amounts of time unpredictably.”

“It has enabled me to collect J from school, take him to the Metro centre (leaving B with BLF carer), and go shopping with J or on his own.”

“I have been able to take my daughter to the GP on her own. I have more time for her without having to think about C all the time. She has to take a back seat all the time.”

### ***Parents’ perceptions of the BLF worker / service***

“Staff were as friendly as I expected and they seemed to enjoy the experience as much as M.”

“It’s good but I need more of it.”

“I had no service at all before this one – completely new – when working well it is superb.”

“One of the nursery nurses could not be left because of lack of experience/knowledge/confidence, but it was at a time when I appreciated any help at all so I was grateful for the kind gesture, however short lived it was.”

“The access and support for the service was over-whelming. The understanding and advice I received was worthwhile for my child and my family.”

“I was told more or less when the worker would come and could then fit in around this – it helped me plan my time.”

“The timing of the service was flexible to fit in around my other commitments.”

“Very good service. Always available for help and support. Could not find any fault with the care of my child that has been given by the team.”

“The service is very friendly. What makes the service - are those employed. The team have on many occasions worked closely together with us as a family to deal with emergencies of varying kinds (both medical and family crisis). Always providing people with equipment, advice and guidance appropriately in times of great need. Well done.”

“The service is extremely flexible and open to suggestions”

“I wouldn’t change the workers.”

“When things go wrong it got sorted very quickly –they are very flexible.”

“They are lovely – I can trust them, feel comfortable around them – have confidence in them. They are conscientious and careful with us.”

“Reliability good – would like more but am aware of staff shortages due to sickness / holiday etc.”

“Lovely, they take an interest in us – don’t judge us – ring when L is not well to ask about him. Treat us like humans. They interact with L – treat him with dignity. They talk to him, explain things to him. They are also very friendly with L and have jokes with him.”

“The service is flexible – we can discuss and agree with worker according to my and her needs. Week-ends available if needed.”

“There is good support from admin – easy to talk to. “

“Very caring workers.”

“I have trust and confidence in the worker – I can go out and be confident that A is looked after and that the worker would ring me if there was a problem.”

“We could trust them to come, reliable service, understanding, friendly, basic medical background which was helpful because could check out concerns, practical, good listener, could talk about anything (family matters etc).”

### ***Parents’ /carers’ perception of relationship / trust building***

“At first we found it difficult to allow people into the home – not easy having strangers in – afraid of being judged in some way – reluctant to have help coming in – fears about having my own space invaded.”

“It was difficult at first having people in the house – but in time we have got used to them.”

### ***Parents’ perception of sickness / holiday cover***

“I received a service for P from March 2004. The second Home Carer came involved in May/June (this carer was to relieve the first one at times of holiday / sickness etc.) This second carer became sick for 6 months and when came back resigned. This has meant that we have not received the service we were promised.”

“The last 6 months we have had a limited service and not the one we had been assessed for. We were originally assessed for 9 hours per week but this was reduced to 6 hours a week in September. We objected to this but it had no effect.”

“We received no service over the summer because of staffing problems” (holiday / sickness).

One parent referred to the issue of staff having their own child care commitments and crises that had resulted in the service to their child being shortened (e.g. carers coming later in the morning [because they had their own child care commitments] and then having to go off to another client thus shortening the service to their child).

“We sometimes can’t get the service at the right times because of staff shortages.”

### ***Access to other Services***

Feedback from service users via the Regional Service User Questionnaire has also highlighted how the BLF workers have facilitated access to a range of other services which include:

- Summer play schemes
- Sponsored child minders
- Toy library
- Portage
- Family Fund Applications
- Rainbow Trust

### ***Parents’ /carers’ suggestions for improving the service***

“Hopefully if this service continues to be funded families that are currently receiving help from this service may be able to receive extra help especially in longer holiday times (e.g. Easter and summer holidays). This will be extremely beneficial to families with children that have severe difficulties and require two or more people to transfer, go out or even take part in outside activities.”

“Should be a permanent service with many more staff for the amount of families in need. I think it keeps the children at home and out of hospital in my experience anyway.”

“I had two different workers coming who alternated week by week so I did not really get to know either of them very much and the service ended by 4pm. Later cover would have been beneficial.”

“I just need more of it!”

“Wish it covered night and weekends but really appreciate what we get.”

“We need more support workers – it’s good what we get but not enough of it!”

“I need more time to enable me to do house work.”

“I think that the time waiting for equipment should be improved. I have been waiting ages for a chair for my child which they badly need for feeding.”

“Our child is hemiplegic but does not receive physiotherapy, other than 1 hour per week group cognitive learning / life skills. We were unaware of the hydrotherapy pool at X for 2 years. We believe the physiotherapy department is vastly under funded.”

“Messages need to get passed on better. Sometimes messages about whether or not M would be at home did not get passed on and workers turned up when he wasn’t there or did not turn up when he was. Not the workers fault – office issue.”

“We need physio – this has been promised but has not materialised.”

“We understood that there would be a night service – this was promised when the service was being planned. This is what would make a real difference to us.”

“I’m very grateful but don’t want to say too much in case the service is withdrawn.”

“I would value greater flexibility – at present there are fixed periods which do not allow for family social activities falling outside the set times” (referring to short break care in residential care)

### **Service Co-ordinators’ perceptions of the impact of the service**

What are the service managers’ perceptions of the impact of the service? The following information is taken from interviews with Service Managers undertaken in December 2004.

I think the main impact from the feedback I get from the parents is that they feel that their child is getting real quality time with someone who specifically knows about their child so it’s not just the child going off with just anybody the carers link into the same families so they’ve got the continuity there – they get to know the children very, very well and they feel really happy because the carer will come and pick up the child and go off to do the session. And the other main thing is that they found that a lot of the time they weren’t able to spend quality time with siblings because the child with special needs was taking up a lot of their time and the siblings could be very, very jealous because this little ‘Johnny’ was getting everybody coming in to see him – he would have the speech and language therapist, the physio, the OT – he was getting all of the attention all of the time and now the parents feel they are able to give more time to the siblings. A lot of the time the children with disabilities you take them out socially and they are quite disruptive so the families would not go out as a family because it was almost this drawing of attention by the child – now they can go off and do other things with their children.

Another manager comments:

The feedback from mums is that they have been able to do things that they probably would never have been able to do – as I say, one of them has learned to drive, one mum just goes out whereas she never used to go out and that is a massive achievement – a massive turn around for that family, another mum comes in from school and goes and takes her little one out and her two older girls because she felt they weren't getting any time because every night they had to be in for this little girl coming in from school. So they go and have a pizza or something – just take the three of them out for a pizza.

Another carer is able to arrange her hospital appointments around the service:

One mum is diabetic so she can arrange her appointments at the practice nurse or at the hospital around one of the girls going to look after the little boy – he's just been in for surgery and they were back and forward with him but if the nursery nurses are in we just go and check his surgical things.

Other tasks parents / carers are able to carry out include:

shopping  
driving lessons at a more convenient time  
return to work

The intensive work by BLF workers can result in children's development in a way not imagined by parents/ carers.

The highlights I think have been the benefits for the children and the benefits for the families. Positive feedback from families about the child's health care. Certainly it has made a difference in people's lives. Things such as the children doing things they didn't realise they could do and we've got one family who has never always resisted – they've allowed us in but not to give any care at all and for the first time ever the nursery nurse has been doing cards with him and pictures with him and those are up on the wall – those are the things that mean a lot to families because they have memories of their children which they didn't have before. It's about children actually doing things which they didn't realise that they could.

Another important contribution of the service is in its work with terminally ill young people and assisting in preparing families and building up memories that the families can retain.

We know some of these children are going to die and we want to build up some positive memories so that the parents can look back and remember fun days not just memories about the difficult challenges and physical care and the grind.

The impact on siblings is also remarked on:

I genuinely think it has made a big difference to the lives of all the people in the families – I think we give them a chance to enjoy themselves and they quite enjoy the fact that we are not just going into the home and looking after the child at home while the family might go out and do something else but also trying to do things with all of them as a family. I think that works very well and I think they appreciate it to be honest and I think that the two workers are both regarded really fondly and they enjoy them going out with the family.

One of the specific things I do know is that it talked about improving the quality of life for siblings and I think we do. I couldn't say for definite, my opinion might be completely different from the parents opinion but we try and do things with them as a family rather than just one child when we do social activities and things and I think that the siblings appreciate something being done for them for a change instead of it always being focused on the child with the problem.

One of the issues that has been highlighted by Service Managers has been the need to look wider than purely medical needs when working with service users. One of the main aims of the BLF services has been to facilitate access of service users to a range of leisure / social opportunities. What have been the issues around facilitating accessing services to increase socialisation?

For all areas this has been a key objective of their work.

So it's not just about going into the house and offering respite to the families so that they can go off and do something, it's about also socially taking the children off to different places ...

One area has built on work already started by St Oswald's.

We have linked in with St Oswald's because before they actually went live as a service they had actually had the staff in post for some time and they had actually gone out around the area to find out what services were available to children who were in wheelchairs etc. So we managed to access their file and then, at the moment this is one of the projects to the CCNs in my team – they are looking at what services there are in Northumberland and North Tyneside and trying to produce some sort of mapping document around that. With regard to North Tyneside there is a federation called the Learning Disability Federation and they are funded by the Children's Fund and they have been up and running for quite some time and they actually link in around social care for children with disabilities but not children with as severe problems as the children that we are linking into.

There have been issues about transporting service users.

There is generally no problem with pre-school children who are quite small – the staff are covered to have the children in the car and travel with them and most of them are just in baby seats. The problems come with the children who are wheelchair bound and it is transportation – that's causing big problems.

And

The babies they are taking out and that's quite easy because obviously they've got their buggy and they are easily accessible – pushing them in the buggy. They have also taken a couple of the younger ones out in the car because they've been able to get the parent's car seat and put it into their car and they have taken them out to the beach or to see the dolphins when they were there. The older ones become a problem because the BLF workers can't get wheelchairs in their cars so they aren't able to take them very far. One of the parents has said, and it would come down to insurance, they would insure the nursery nurse to go out in their car but then I have to look at that because it is a big issue because we are not just covered by their insurance you've got to have the insurance from work as well.

What expectations should we have around how transport / special activities should be paid for? This was not part of the original funding bids.

Both really because there hasn't been any funding put aside around transportation. These families do receive disability and mobility allowances but although that is directed at the children it's not something they are always wanting to ... it kind of gets absorbed into general family things.

Another issue for some staff has been how the BLF worker's admission to various social activities should be paid for.

I would like to see that develop more because I questioned our business manager about, say, they were going to the pictures and obviously the child's parent would give the money for the child's admission and I assumed the BLF worker could claim back anything she spent say on the admission to the pictures and I was told that that would have to be looked into because the carers can get some discount but it wasn't confirmed that they could be reimbursed so I wouldn't let them go unless I know they are going to be reimbursed. So unless they are prepared, at the other end, to say we will reimburse them then they won't be going to places that cost money.

Lack of facilities has also been an issue.

I think the social needs have been more difficult to meet because of the lack of facilities. It's trying to find what is available in what area and it's not only just finding what is available, you can find something available but how do you physically get the child to that facility.....So I think the social part has probably been the most difficult – it's been easier for the children who have accessed short break care within a residential facility, it's easier for the children who you can transport by car but for the children who have probably got maybe not the most complex needs but the children who are physically are probably more difficult to get out and about still aren't accessing necessarily – although you can take things into the house and do things with them in the house and that certainly has happened and I think that has been quite a positive experience for parents but the social bit doesn't work quite as well because they've got all these Sure Starts and clubs and

leisure facilities but they aren't always available for children with disabilities or they don't actually live in the areas covered by it.

We keep finding new places – we're quite good at looking at what's available here and there in places that you wouldn't necessarily think you could access. It's especially difficult I think we are finding now with the dark nights because where do you take a child on a dark evening.

### ***Link to multi disciplinary working***

Greater multi-disciplinary working has also brought benefits to service users. The BLF workers all receive training through the CCN team. They also undertake work on behalf of other professional groups (such as physiotherapists etc). In doing this work, at times they both replace existing service (i.e. carry out tasks instead of the professional) and / or also extend the service (i.e. offer more of the service than would normally have been possible. Where this happens the BLF workers, because of their frequent contact with service users can "build in" this work to suit the service user. The use of BLF workers linked into existing professionals has also made service delivery less complicated and more understandable from the service users' perspective. One manager describes this thus:

Service users feel that the co-ordination of services has improved because what I try to get the staff to do is to link in if they have a speech and language worker or a an occupational therapist or a physiotherapist – I try to get the girls to link in when they are having those therapies to find out what they are doing and then continue those therapies. Sometimes they're not just in for one session, sometimes the speech and language therapist might only be in once a fortnight whereas my staff might be in 2/3 times a week. So they are carrying on that really intensive therapy for them and I have had feedback from a particular physiotherapist saying one of the children has come on absolutely leaps and bounds since our health care worker has been linked in because she has been able to carry on that work and this child is nearly walking now and she said she just couldn't have foreseen that 8/9 months ago.

Another Service Manager comments:

The programmes are still coming from the appropriate professionals and supervised by them but there is a quicker response from the children because they are getting more quality input really.

The importance of developing close working relationships with CCN teams has been highlighted:

The only potential problems are within the CCN team and I think they find it quite difficult because they have worked with these children for years and then suddenly our team has come along and we've obviously got very in-depth involvement with these children and I think they find that quite difficult. So it's about looking at communication between our team and the CCN team and trying to build on that. The CCNs cover out of hours and weekends and things like that so they might be called out to the families to

do different things so it's just really about encouraging communication. For example, if they have gone out to see one of the children to feed that back to the health carers who are going in that week.

### ***Increased confidence in services – gateway to other services***

For some families experience of and developing trust in the BLF workers has resulted in them being prepared to accept services they might not have accepted previously.

We've done a lot of referrals from our team to St Oswald's because once we've got in and started to work with these families and they've gained confidence in having respite when previously they wouldn't have dreamed of sending their child into St Oswald's but now they realise other people can help to look after their children and they feel quite comfortable now sending them to St Oswald's now whereas in the past they have been very protective of their children because they've never felt there were the professionals there to look after their children to a standard they would be happy with. With us going in as a team has made their confidence in the services grow.

### **BLF workers' perceptions of the impact of the service**

The following are some of the benefits perceived by the BLF workers. These were derived from a Workshop for the BLF workers held during November 2004.

- Benefits for the children include being taken out and about – when this would not otherwise be possible – workers also able to take all necessary equipment with them.
- Benefits to family – parents catching up with sleep, going shopping without wheel chair, getting time with siblings.
- BLF workers not seen as professionals – families gain greater confidence in, and more open with BLF workers.
- Currently no uniforms used - to minimise formality.
- Parents going out together for the first time in two years.
- Become part of the family.
- Have followed children onto ward when admission has become necessary to assist and advise nurses thus ensuring continuity of care.
- Enables parents to have a chance to spend quality time together – relief to parents.
- Flexibility for children/families – some staff work over 24/7 (although there are differences in the different areas around what days / time periods are covered).
- Become part of the family – seen as friend rather than professional.
- BLF workers sign posting to other services – helping to negotiate involvement of other services. Building trusting relationship with family to encourage families to access services they had previously been wary of accessing.
- Age of worker – one worker being seen as parent figure where young mum had lost her own mother.
- Some of trust given by families comes from workers being employed by health – perceived credibility in dealing with health related issues.

- Language barriers – one family – mother French / father German – BLF worker acting as “interpreter” – helping family negotiate with agencies.
- BLF service supports other professions and extends this provision (e.g. workers undertaking tasks on behalf of OT, Physiotherapist, Speech and language therapists).
- Chance for parents to go out/sleep.
- Support to families in communicating with other professionals e.g. contact with medics.
- Families can offload their feelings to workers.
- In the main the services try to offer continuity for families – same worker – to enable effective working relationships to build up.
- Families find it easier at times to question the BLF worker rather than the nursing team (some families are “afraid” of professionals).
- Rota – ‘know where you are at’.
- BLF workers bring different skills and experience to the work which complements that of the other professionals.
- Enables families to do ordinary things – sleep, shopping etc. Enables children to participate in ordinary activities (which they wouldn’t be able to without support).
- Easier for families to accept BLF service (not so formal/professionalised).
- Families say they want more of it and longer.
- Families are very grateful even though (for one care worker) it can be short term help.
- Sometimes workers are advocating for the families to the CCN (e.g. they might ask the CCN to re-assess if they realise that the family still need more help).
- Families open up to the carers more because they are with them longer – uncover needs that parents might not raise with CCN on their own. Parents so grateful for help they often don’t want to ask for even more. (One worker described a situation where a mum had three children, two of them were autistic plus a baby with Down’s syndrome – in between feeding the baby she was up most of the night as usually one child would awake and not want to go back to bed and this would wake the other child up. The worker could see the mounting problems and physical exhaustion and asked for more help for the mum. )
- Some parents may not like doing some of the tasks e.g. changing the tracheotomy tube on their baby so they will ask the worker to do this – gives them some relief from this job.
- Relief/respite (from isolation).
- Comfort/support.
- Socialisation – the worker may be the only other adult the parent sees through the day.
- Workers suggest new opportunities to the parents.
- Siblings enjoying ‘a fresh face’.
- Enables parents to get out of house.
- Giving carers time for themselves, partners, siblings (gratitude!! – want more!).
- Support – someone to talk to – increases choice/gives freedom.
- Advocate for carers – worker can speak up for them.

## Professionals' views on the impact on the service on parents and children:

The group of professionals who were interviewed include CCN's, OT's, Physiotherapists and Speech and Language Therapists (see section 11 for further details). Their perceptions of the impact were as follows:

Impact on parents	Impact on children	Other Impacts
<p>"huge impact, once parents realise they are in need of help. A lot of confusion at first regarding what the service provides. When it works, it works really well."</p> <p>"Provides lots of benefits, as parents in need of some free time. Parents give positive feedback that it makes life a lot easier"</p> <p>"Huge impact as benefits all"</p> <p>"Offers a lot of emotional support, gives a positive reinforcement, helps parents make decisions, facilitating advice."</p> <p>"very positive BLF workers are very important especially after a discharge, as most effective way to find out how the family are managing."</p> <p>"Gives parents a lot of extra support, is a weight lifted off their shoulders. Don't feel guilt ridden as receive respite without having to go into a hospice"</p> <p>"yes by allowing them to have time with a knowledgeable worker"</p> <p>"valuable- appreciation, workers part of the family"</p> <p>"gives them a well deserved break"</p> <p>"definitely changes their lives"</p>	<p>"meet new people"</p> <p>"make new friends"</p> <p>"Gain huge benefits, allows them to see a different face, 1-1 attention, where mam may not have time to spare, the service gives children quality time, service is brilliant as no other in area"</p> <p>"provides a more consistent approach to the child which has been proved to be more effective. Also promotes development, strong emotional bonds"</p> <p>"can allow kids to access school"</p> <p>"gives the kids a break and enhances child care"</p> <p>"love the BLF worker visiting, as form a good working relationship"</p> <p>"activities such as listening, talking, massaging etc"</p> <p>"allows child to be more socially integrated, amazing when you see a child who cant communicate laughing and enjoying themselves"</p> <p>"high level of stimulation, helps with individual development"</p> <p>"gaining respite whether having to go into hospital, allows them to gain one-to-one attention"</p>	<p>"negative, when after 12 weeks the service comes to an end, as child can not understand why the service has been broken"</p> <p>"service is another communication channel so can gain a better understanding of family needs. Most important component is the flexibility that the service offers"</p> <p>"May help keep the kids well and not having unnecessary visits"</p> <p>" positive affect on siblings"</p> <p>"can offer unbiased pair of ears to listen too"</p> <p>"workers include siblings as much as possible"</p>

## **Summary**

The views from four perspectives (BLF workers, parents / carers, Service Co-ordinators and a range of professionals) are all indicating similar benefits and challenges of the BLF services and are fairly evenly spread across all of the services.

This should encourage confidence in the findings from the evaluation of the impact of the services.

The starting point for this analysis is that children and young people's welfare is intricately bound up with that of the welfare of their families and a significant amount of evidence has been collated that indicates benefits directly to the young person and other members of their family. This is consistent with the definition of palliative care as:

‘An active approach and total approach to care to children with life threatening/limiting conditions and their families. It embraces physical, emotional and spiritual elements for the whole family to enhance their quality of life. Symptom control, reducing emotional impact on family members, provision of respite care and bereavement care following death are all included.’ (NOF, 2002).

The above perceptions of the impact of the service can be summarised as follows using the current Every Child Matters Outcomes Framework.

### **Linking BLF impact measures to the Every Child Matters Outcomes Framework**

All of the above impact evidence can be linked to the Every Child Matters Outcomes Framework.

<b>Every Child Matters Outcomes Framework</b>	<b>Impact Evidence</b>	<b>Comment</b>
Be healthy	Parents have been helped to ensure their children are physically and emotionally healthy	The main issue that has reduced the impact of the service on all of the outcomes has been either a reduced service or no service due to staff shortages (due to sickness or holiday).
Stay safe	Reduced pressure on parents will reduce the likelihood of stress related abuse and promote security and stability of families and support parents in caring for their children.	Transport has also been an issue with older children with complex needs.
Enjoy and achieve	Services have contributed to the personal and social development of young people and their access to recreation.	The lack of appropriate facilities has reduced the possibilities for socialisation.
Make a positive contribution	Young people, their siblings and carers have been helped to develop socially and develop self-confidence.	
Achieve economic well-being	In some cases parents/carers have been able to return to work through support from the service. This will enhance the economic well-being of the family unit.	

## Section 11: Perceptions of a range of professionals involved with the service

Using semi structured interviews data was sought from 12 professionals involved with the BLF services.

Table 11.1 shows the title and role of the professionals who were interviewed.

**Table 11.1**

<b>Job Title</b>	<b>Job Role</b>	<b>Numbers Interviewed</b>
Community Children's Nurse	Looks after children with complex health needs, supporting children and families both clinically and emotionally.	8
Occupational Therapist	Health and social orientated, helping children develop co-ordination, housing, respite and fostering. Adaptations providing schools with necessary equipment and manual handling.	1
Speech and Language Therapist	Assesses and manages children with severe complex health needs.	1
Physiotherapist	Works in hospital care setting and has a caseload of pre-school children as well as working in mainstream and special schools. Show how to access educational curriculum and equipment.	1
Portage Worker	Training, Supervising, Assessments, Supporting Families.	1

Table 11.2 shows the length of involvement of the professionals, the numbers, level of involvement and relevant comments made by them.

**Table 11.2**

<b>Length of involvement</b>	<b>How many</b>	<b>Level of involvement</b>
Since the beginning	11	<ul style="list-style-type: none"> <li>• Introductions</li> <li>• Training</li> <li>• Referrals</li> <li>• Risk Assessments</li> </ul>

These professionals made the following comments about the various processes relating to the delivery of BLF services

## **Referrals**

- “Has made two referrals, initially thought whole process created a lot of work but now realises it’s very worth while, and that it makes a massive difference to the families lives. Referral via telephone discussion followed by referral form.”
- “Now that the service is well established, the referral can be up and running within a few days, it’s now a very easy straightforward process.”
- “One implication arose when a referral could not be processed due to a training issue, there was no one available to train the worker regarding lifting a child, the referral ended up being pushed backwards and forwards meanwhile the family had to struggle.”
- “Once I have referred a child I don’t have much involvement afterwards as nursery nurses devise their own care plans.”
- “Referral process less formal as team is integrated.”
- “If could use e-mail to refer, process would be quicker and more professionals may refer.”
- “Referral process can be time consuming.”
- “Had many referrals refused, deters referring any more.”

## **Planning**

Most were involved in panning the care package.

## **Risk assessments**

- “Not enough room on forms to give an in-depth assessments.”
- “Co-ordinator contacts me regarding advice on manual handling and risk assessments. After assessing the family home I spend time talking through the findings with the workers.”
- “Co-ordinator contacts me when the service is involved with my personal caseload; I then conduct a clinical risk assessment.”
- “Uses a basic form as a guide.”
- “Risk assessments conducted in family home after a discussion at base.”
- “Not involved as somebody from health and safety conducts these assessments.”
- “Like the blind leading the blind, regarding referral forms.”

## **Reviewing**

Most remained involved and were part of the review process.

- “I personally do an ongoing evaluation, to make sure everybody is happy and that there are no problems.”

## **Training**

All 12 of the professionals were involved in training in some way.

- “Questioned whether service was worth it as training took up a lot of time.”

- “I feel that a lot of the training is not documented and that this is a vital aspect to be improved.”

**Table 11.3 Professional involvement in training**

<b>Format</b>	<b>Duration</b>	<b>Comments</b>
Practical supervision, Theory followed by training on dolls, then on the child	As long as necessary	Supports workers until confident. really enjoy training as gain personal satisfaction
Shows the workers how to approach children and to interpret children’s behaviour.	Lot of work potentially, cant commit to service due to understaffing of personal team	
Lecture environment, question and answers, written documentation, training individual basis.		
Shows workers how to position child and how to conduct chest physio, as well as applying splints in home and school		Not creating anymore work
Intense training providing basic skills and background knowledge. Training in family home with child	Creates a lot of work	Takes a lot of work, takes a long time for CCN and parents to gain enough confidence
Awareness in family home, then practical training. Feels that natural nursing practice is more effective than theory	Tracheotomy more time consuming	Observes until confident with workers and that workers are comfortable with situation

***Professionals’ perceptions of the BLF workers***

“workers are lovely and dedicated and are a good example, the support they offer is spot on.”

“positive ... very eager to learn, they ask a lot of questions, which show they are interested!”

“very receptive ... eager to learn. Although it’s unnecessary for the hierarchical environment. Very inappropriate manner to have to run everything past them, this can intimidate the workers.”

“very co-operative and eager to learn.”

“very good working relationship with workers, feel they are very keen to take on technical stuff.”

“workers are very eager to learn, and are brilliant at taking on lots of different clinical skills.”

“very positive, they have a huge responsibility which must be daunting if workers have no previous background.”

**Professionals’ views on the impact on their own workload**

**Table 11.4 Professionals Views on the impact on their own workload.**

<b>A lot of work initially then decreased</b>	<b>Continual impact</b>	<b>Hasn’t as yet but has potential</b>
<p>“service very flexible and accommodating”</p> <p>“ everything was new, so a lot of work at the very beginning”</p> <p>“made me question whether service was worth being involved with, now realises it’s a godsend. It’s worth the initial workload increase”</p>	<p>“designated BLF CCN should have more input, and take over training of all workers to reduce the referrers caseload”</p> <p>“part of role as CCN”</p>	<p>“As of yet the visits have coincided with my personal caseload”</p> <p>“Does take up time but not extra case load”</p>

This shows that the impact on caseloads has varied and it would be useful to explore this in more detail to understand it more.

**Professionals’ views on the impact on hospital, GP and CCN visits/admissions**

Professionals were asked to give their views on how the BLF service had impacted on other services.

**Table 11.5 Professionals' views on the impact on hospital, GP and CCN visits/admissions**

<b>Hospital</b>	<b>GP</b>	<b>CCN</b>
<p>“ Impossible to say, only time that admission would be needed would be if the parent was unable to care for child”</p> <p>“ has an impact, means parents can access things correctly, so therefore admissions may be reduced, so don't use hospital for respite”</p> <p>“ Could have an impact as it means kids are kept at home longer”</p> <p>“parents use workers for reassurance, as parents tend to be over protective this can stop stress building up and reduce demand on other services”</p> <p>“ workers relieve the anxiety that parents may have”</p> <p>“definitely reduces admissions as gives proactive response”</p> <p>“yes eliminates families concerns which often lead to “social admissions”</p> <p>“Hope not, service is not for this”</p>	<p>“ Impossible to say”</p>	<p>“ Impossible to say, but would imagine it would decrease amount of visits”</p> <p>“ May cut down to some extent”</p> <p>“ yes definitely BLF workers can take some of our duties”</p> <p>“Allows girls to gain some satisfaction, knowing family needs are being met, nice to have input in new service”</p>

The issue of impact on other services is critical in developing an understanding of the overall costs and benefits of the new services. This is an issue that could be followed up in future research.

## Professionals' overall views on the service

**Table 11.6 Professionals' overall views on the service**

Positive Comments	Negative Comments
<p>“service is priceless, no other in area so used more frequently”</p> <p>“very supportive and helpful”</p> <p>“workers prevent the kids from missing out”</p> <p>“Has a massive effect regarding access to education”</p> <p>“Improves quality of life for parents and children”</p> <p>“workers work well, families see workers as friends and trust them more than other members of multi disciplinary”</p> <p>“allows a better form of communication, gives greater insight into families and any issues regarding them.”</p> <p>“never heard any negative comments and feels that the parents are very appreciative, and grateful of the help”</p> <p>“now service is up and running everything is very straightforward and easy”</p> <p>“very beneficial, it’s a long time coming, which is absolutely fantastic”</p> <p>“service is a godsend, worth the initial workload increase, have seen a massive difference in the children’s quality of life, since the service has had an input”</p> <p>“offers a lot of help that wasn’t previously available”</p>	<p>“Criteria should be widened, so everyone can benefit” <i>(This was mentioned several times)</i></p> <p>“Not enough staff employed, as well as lots of sickness among small team of staff”</p> <p>“More joint working and more training hugely beneficial”</p> <p>“Should be priority to let other professionals aware of BLF involvement”</p> <p>“Professionals should be aware of what the service actually provides and the referral process”</p> <p>“CCN’s should gain more feedback from the workers, and more structure needs to be in place, caseloads need to be discussed privately”</p> <p>“there needs to be regular updates regarding the service, service needs to blow it’s own trumpet”</p> <p>“communication needs to be addressed”</p> <p>“isn’t good practice for co-ordinator to want to know absolutely everything, will make the workers feel unapproachable and inadequate”</p> <p>“I regularly question myself whether to refer as services creates a lot of work, wonder whether it’s worth the hassle”</p> <p>“Many issues regarding manual handling, would like to be more involved with the clinical supervision of workers, and doesn’t feel comfortable with individual caseloads being discussed”</p> <p>“team is very small at the mo, a lot of very unhappy staff at the beginning”</p>

<p>“An example, mam of one of sick children was suffering from depression, and for five years had struggled alone as mum would not send child for respite, as she felt she was failing her child and was guilt ridden. However parents finally agreed to BLF workers could go into stimulate the child. The parents love the service, and feel that it has changed their lives completely.”</p>	<p>“staff should be rotated more so parents don’t rely on the individual workers”</p> <p>“should try and improve hours the service provides at weekends when families need it, more staff”</p> <p>“needs to be faster communication and standardisation of rules and responsibilities. Service would fall apart if not for the co-ordinator”</p> <p>“high turnover of staff works against continuity”</p> <p>“not letting other professionals of whom are involved with a particular child aware of the BLF service involvement”</p> <p>“Should keep the 12 week deadline for everyone”</p> <p>“workers should be introduced informally to the family first, to help build up trust”</p> <p>“communication needs to be addressed as it is very poor”</p> <p>“A more professional name other that BLF”</p> <p>“Should be a designated worker for training manual handling”</p> <p>“Very little contact with workers”</p> <p>“would like to gain feedback from workers regarding the families”</p> <p>“more structure needs to be put in place to discuss private caseloads”</p> <p>“If could gain more funding it would allow the workers to be allocated to the families so that they don’t have to rebuild the trust with another worker”</p> <p>“ service is woolly in areas but feels it’s fair enough”</p>
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The key issues here appear to relate to: the positive benefits of the service, the criteria for receiving the service, communication, the introduction process, the importance of building up trust and flexibility (namely in relation to the hours that BLF workers are available).

## **Section 12: An understanding of the ways in which the three BLF programmes have worked together to inform delivery of their services**

The main way in which the various BLF services have worked together is through the Regional BLF Operational Group.

The Regional BLF Operational Group was formed in April 2004. It comprises the Service Managers of the BLF services and representatives from the Strategic Group. It meets approximately bi-monthly.

### **The aims of the group**

The following aims were agreed:

- To offer mutual support and networking.
- To share a range of relevant documentation to avoid duplication.
- To reflect on developing practice and to learn from this (“There is no failure, only feedback!”).
- To act as a link between the operational and strategic level.
- To promote multi-disciplinary working.
- To identify and address mutual training needs.
- To provide a forum to “Tell the N.O.F story” and try to capture.
- The complexity of the implementing new ways of working.

Each meeting usually follows a similar format and the following issues are generally discussed at each meeting:

- Information sharing on operational issues from each service.
- Feedback on training courses attended.
- Information on forthcoming training courses.
- Feedback from Audit Forum.
- Identification of training needs.
- General problem solving around a range of issues.
- Recruitment and retention of staff.
- Numbers of referrals.

Table 12.1 shows part of the minutes from an early Operational Group which gives some indication of the sharing and mutual support that the group has offered members. Many of the actions recorded include sharing job descriptions, policies and procedures, assessment processes and training schemes.

**Table 12.1 Agenda of Operational Group April 2004**

<b>Discussion Point</b>	<b>Information</b>	<b>Action</b>
Staff recruitment	Home care: Different grades / qualifications and job descriptions. Some staff issues arising around flexibility and unsocial hours.	Collate Job descriptions
Health and Safety	Issues of supervision, training, health and safety, Risk assessments. Need to ensure workplaces (i.e. service users' homes) are safe for staff). On call arrangements	Collate and share relevant information.
Tasks undertaken by staff (Home Care)	Related to job descriptions / qualifications etc (see above). Map changes over time.	Share procedures that address these issues
Staff training	Need to ensure appropriate training is given to the range of staff (e.g. tracheotomy care etc).	Share details of training provided. Agree joint training across areas. Commission external training where appropriate.
Referral criteria	Level of referrals at present low but likely to increase soon. Variability in how referral criteria are being agreed – some through local multi-agency discussions, some “organically”.	Collate and share referral criteria / forms.
Service users	Need to collate information about these	Collate and share relevant information.
Assessment Tools	A range of tools were identified	Collate and share assessment protocols
Service agreements	These are agreements with service users	Collate and share
Information leaflets	A range of information is being prepared for professionals, and service users.	Collate and share information leaflets
Impact / outcomes	Share specifying of outcomes.	Collate and share relevant information.
Interventions	Information given re development of psycho-social approach (Bereavement strand)	Collate and share relevant information.
Baselines	Some “mapping” of current system to identify the impact of the new service.	

One manager describes the development of the group thus:

At the beginning there were issues regarding consent to give medications and things like that which obviously are things that I hadn't thought of – we have got round it. Obviously it has to go through ratification with the Trust to make sure it is passed by clinical governance.

We no longer talk about procedures etc. Because we are all up and running now and we've got everything set in place. It's just now the problems that arise individually and you just have to try to reflect on them and see how you handle it.

More recently there has been greater reflection on the nature of the service, numbers of referrals and future need for such services. Thus one member of the group comments:

I think the more time I spend doing this job I think the more that need is going to grow. There are more of these children with complex care needs and life shortening conditions coming through simply because of technology – premature babies is an example.

It might not be that they are palliative at that time it's more of a complex thing. The children I am taking on now they are not palliative at the end stages they are long term and these nursery nurses could be going in for years.

Further possibilities for service expansion have also been noted. One member informed the group:

I had someone from Early Years in Newcastle tell mum to ring me to ask if she could have the NOF service because I could refer her and so this mum rang up and I asked her why she wanted the service and she wanted it so that she could go back to work and she wanted this person to help with the child care in the nursery. You think that would be an ideal thing but is it for BLF to be funding something like that and in the end I decided "No, I couldn't legitimately". And yes this child probably does have palliative care needs but whose needs were we meeting because the social workers would say is it the child who needs respite or is it the family.

Thus as the services have developed the focus of the group discussion has moved from the practicalities of getting the services up and running to greater reflection on processes.

The future of the services is also starting to emerge as an issue and this relates to the way that services were set up in the first place (some services offering substantive contracts, others fixed term contracts).

All of the aims set for the group have been achieved and the continuing high attendance is testament to its continuing usefulness.

## **Organising training**

One of the key roles of the Operational Group has been to organise training for the BLF workers.

Initially a training day was organised to bring BLF workers together to celebrating the achievements of the BLF workers so far and to discuss and identify training needs with the BLF workers.

The aims of this day (held in November 2004) were:

- Celebrate the work to date.
- Enable the various areas to share experiences of their work.
- Identify the benefits / challenges of the work.
- Identify future training / support needs.

The following training needs were identified:

1. Dealing with bereavement – for both family and worker
2. Therapeutic play, communication skills, play skills
3. Working with children who are disabled visually
4. Basic counselling skills (e.g. listening, responding etc)
5. Dealing with boundary issues.
6. Palliative care skills

In response to this a programme of training has been initiated organised through the Operational Group. A Workshop on Bereavement was held in February. This was run by the Barnardo's Serious Illness Team. The evaluation of this workshop can be seen in Appendix 1.

Further training will be planned by the Operational Group. The current priority is focussed on developing communication methods with the children / young people receiving the service. A workshop is being organised and a date arranged for June 2005.

## **Barnardo's Serious Illness Team and Sunderland Counselling Service**

Both of these services were part of the original NOF/BLF bids.

The Serious Illness Team is managed by Barnardo's and covers Northumberland and North Tyneside and Newcastle / Gateshead.

The Sunderland Counselling Service covers Sunderland and South Tyneside.

The service workers have:

- Attended multi-disciplinary team meetings.
- Provided support to BLF home care workers who have experienced stress within their working situation (e.g. the death of a child they had been supporting).
- Provided training on bereavement issues to individual teams.

- Organised a BLF Workers' workshop focussing on bereavement.
- Regularly attended the Regional Operational Group.

Both services have been subject to separate evaluations. Details of these can be obtained from:

Angela Edwards (Barnardo's Serious Illness Team)  
([angela.edwards@barnardos.org.uk](mailto:angela.edwards@barnardos.org.uk))

Andrew Local (Sunderland Counselling Service)  
([AndyLocal@loki1.fsife.co.uk](mailto:AndyLocal@loki1.fsife.co.uk))

## Section 13: Executive Summary of Literature Review

This review explores several important themes, related to effective service delivery, which emerge from the relevant literature, and links these to the aims of the NOF/BLF services and the research. Key themes identified include:

- Individualised care, negotiated with child and family, which is compatible with their lives.
- Technically competent carers, who have good interpersonal skills and insight into the family's situation.
- Effective coordination of service and continuity of care delivery.
- Opportunities for the child to access stimulation and social interaction, with increased access to activities outside the home (if appropriate).

Table 13.1 relates the findings of the literature review to the aims of the BLF services and the findings of the research.

**Table 13.1**

<b>The Lit Review suggests</b>	<b>The BLF services aimed to:</b>	<b>The BLF research suggests</b>
Individualised care, negotiated with child and family, which is compatible with their lives	Plan care with families to fit with their daily schedules, and adaptable enough to cope with their changing needs	Where resources permit families have commented favourably on the flexibility and adaptability of the service.
Technically competent carers, who have good interpersonal skills and insight into the family's situation	Recruit staff who had good interpersonal skills and some insight into the families' needs, and to train staff in the care required by the individual children	BLF workers are trained and supervised by the professionals on whose behalf they carry out a range of tasks. This is the main "quality control". Families have commented on both the skills of the workers and the informal, personal nature of service delivery.
Effective coordination of service and continuity of care delivery	Coordination of care delivery through existing community nursing service	An issue to be addressed here is the extent to which packages of support are jointly planned and implemented by health and social care. At present coordination falls mainly to CCN's
Opportunities for the child to access stimulation and social interaction, with increased access to activities outside the home (if appropriate)	Staff who could spend time with the families and involve the children in a range of activities	This has been one of the hall marks of the BLF services so far subject to limitations, at times, on availability of staff and leisure opportunities.

The main issues that have reduced the impact of the service have been:

- A reduced service or no service due to staff shortages (due to sickness or holiday).
- The lack of appropriate transport particularly in respect of older children with complex needs.
- The availability of appropriate social and recreational facilities has reduced the possibilities for socialisation.

The full Literature Review can be found in Appendix 3.

## **Section 14: Conclusions and suggestions for further evaluation work**

- There is strong evidence of a range of positive outcomes for young people, parents/carers and siblings resulting from the BLF services.
- The data from parents/carers, questionnaires, service co-ordinators and BLF workers are all telling a similar “story”. This should encourage confidence in the findings contained in this report.
- It is important to bear in mind that this report represents a point in time where the several BLF services are still very much developing and learning from their experiences.
- Particular issues that have arisen which would merit discussion at this time include:
  - The great emphasis placed on the social needs as well as health needs of service users.
  - The recruitment and retention of staff (in particular the link between the hours for which staff are employed and the flexibility of the service).
  - The affect on small staff groups of staff sickness and holidays.
  - The extent to which the services in practice are jointly “owned” by health and social services.
  - Further work on what the actual need for the services might be in the future.
  - The wide range of tasks undertaken by the BLF workers which include both substituting for and extending existing service provision (i.e. CCN, Physiotherapy and so forth).
  - The potential for developing the role of the “multi-purpose” BLF worker to expand multi-disciplinary resources in the community.
  - The impact of the BLF services on the increase or decrease in demand for other services e.g. short break care, community based multi-disciplinary services, hospital admissions, GP contact and so forth.

## **Section 15: Appendices**

## Appendix 1: Training Feedback

**Barnardo's Serious Illness Team BLF Training Evaluation**  
**Training Delivered at Riverside Centre 23/2/2005**  
**Focus of training: Bereavement and Loss**

**Total number of evaluations received= 12**

**Evaluation areas:**

**1. How far did the course achieve its aims?**

- 100% of respondents felt the course had achieved its aims

**2. To what extent did the course meet your personal expectations?**

- 100% of respondents felt the course met their expectations. Two respondents would have liked more in-depth information.

**3. Ratings: On a scale of 1-6 (1= poor, 3= okay and 6= very good):**

- Responses were all either score 5 or 6

	<b>Total- Score 5 (Good)</b>	<b>Total- Score 6 (V. Good)</b>
<b>Presentation</b>	<b>9 (75%)</b>	<b>3 (25%)</b>
<b>Content</b>	<b>9</b>	<b>3</b>
<b>Handouts</b>	<b>3</b>	<b>9</b>
<b>Venue</b>	<b>3</b>	<b>9</b>

**4. Any Comments?**

- "Really enjoyed the day"
- "Very enjoyable"
- "Thanks"
- "Very informative and easy to understand"

**5. Areas for future training?**

- "more in-depth training" (x2)
- "Development & play therapy"
- "How newly trained staff could approach death"
- "More of the same type of training"
- "More case studies as these generate good discussion"

## Appendix 2: Monitoring Form

<p><b>CHILDREN'S PALLIATIVE CARE SERVICE</b>  <b>BIG LOTTERY FUND</b>          Time period from (beginning of service): .....          to 28<sup>th</sup> February 2005</p>	<p>Supported by</p> 
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**Please insert numbers from when your service started until end of February 2005.**

**BLF Area: (e.g. Sunderland , Newcastle etc):.....**

<b>Gender</b>	
Female	
Male	
<b>Total</b>	

<b>Age</b>	
0-5 years	
6-11 years	
12-17 years	

<b>Referrer</b>	
CCN	
School Nurse	
Social Worker	
Health Visitor	
Other (specify)	
Other (specify)	

<b>Number of deaths</b>	
-------------------------	--

<b>Referral Status</b>	
Total accepted – service allocated	
Total accepted – service not yet allocated	
Total declined – do not meet criteria	
Total declined - by service user	
Closed	
Awaiting Transfer to SSD	
Transferred to SSD	

<b>Ethnicity</b>	
White British	
Other (specify)	
Other (specify)	

<b>Nature of referral</b>	
Life limiting	
Life threatening	

**BLF workers activities**

**Please insert numbers of current service users to whom the following activities apply**

<b>Activity</b>	<b>Numbers</b>
Tracheotomy	
Gastrostomy	
Naso-gastric tube	
Ileostomy	
Other (specify)	
Work on behalf of CCN	
Work on behalf of OT	
Work on behalf of Physiotherapist	
Work on behalf of Speech and Language Therapist	
Other therapeutic work (specify)	
Other therapeutic work (specify)	
To offer emotional support to parents/carers	
To enable parent / carer to go to work	
To allow free time for parents/carers	
To allow parents/carers to spend time with siblings	
To facilitate socialisation of young person	
Facilitating access to other services	
Meeting the learning and development needs and stimulation of the child	
Direct work with siblings	
Other	

**Post Codes**

**Please list out post codes and numbers (please add more rows as needed)**

<b>Post Code</b>	<b>Numbers</b>

## Appendix 3

### Literature review

#### Background

There are a growing number of children in the UK with life-threatening/limiting conditions who are now surviving into young adulthood (Joy 2005). These children have little hope of a cure, and their conditions are those from which people die. They may be dependent on others for basic care from birth, or may suffer progressive deterioration in their abilities. Some children will be able to participate in normal childhood activities, whilst on supportive treatment, but others will be unable to achieve such levels of independence. It is estimated that there are 25,000 children under 19 with life limiting conditions in the UK (Joy 2005). These children have on-going care needs, which are often met within the family home with some support from statutory bodies and voluntary agencies. In 2001 in the North East there was recognition of gaps in service provision for these families (Castle and Lenehan 2001) and following a successful SHA bid to the New Opportunities Fund (which later became the Big Lottery Fund) a home care service was developed. The services were to be tailored to the needs of each individual child, community based and flexible. The development of these services preceded the publication of a vast number of reports, guidance and policies relating to children and young people (ACT 2003; DH 2003; DfES 2003; Bristol Royal Infirmary Inquiry 2001). Despite this the BLF services reflect the key messages from these documents and demonstrate their implementation in practice.

*“There is now, for the first time in many years, an explicit commitment from Government to improve the lives and health of children and young people in England” (Aynsley – Green 2004, introduction to NSF).*

Messages from a number of reports, most recently Laming and Kennedy (Department of Health 2003; Bristol Royal Infirmary Inquiry 2001), have highlighted the extent of reform needed in children’s services provision, and these challenges have been drivers for the “Change for Children” agenda. The Children Act (DfES 2004) provides the legislative framework required for the implementation of the vision which is expressed within Every Child Matters: Change for Children (DfES 2004). The National Service Framework for Children, Young People and Maternity Services (DfES 2004) sets out the explicit standards required. It is recognised that such radical changes may take 10 years to achieve.

In acknowledgment of the demands on the workforce the Government has developed the Children’s Workforce Strategy. This identifies the national and local actions necessary to recruit and retain staff, to strengthen inter-agency/multi disciplinary working and to develop leadership and management. In addition, a common core of skills and knowledge for the children’s workforce has been identified (DfES 2003; [www.everychildmatters.gov.uk/key-documents/](http://www.everychildmatters.gov.uk/key-documents/) ).

The overarching aims of “Every Child Matters” are that each child should be able to be healthy, to stay safe, to enjoy and achieve, to make a valuable contribution and have economic well-being. The key principles emerging from these documents is the need for different agencies to work in partnership to deliver a service which is child centred and meets the needs of individual children and their families.

In submitting the local bid for New Opportunities Funding, different agencies had to work together, and this cooperation has continued throughout the development of the services, at both a strategic and operational level. In order to achieve the desired flexibility in service delivery, each of the partner organisations has tailored their provision to best meet local needs. These needs had been identified repeatedly during previous consultations with families (Castle and Lenehan 2001; Cripps 2000; Cardwell 2002; Duke 2002), which highlighted deficiencies in existing services, for children with life limiting conditions.

The local views on service gaps and future developments required, clearly echoed the wider picture, reflected in national studies and reported in the literature. Several important themes emerge from the literature, which need to be taken into account in providing a service for this group of children. These include the individual nature of children’s needs, the impact of the child’s needs on the family, the “burden of care” and the changes in “needs” and “burden” at critical times. There was also consistency in the literature about the gaps and pressures identified in services, and in the factors that contributed to effective interventions.

When Commissioners are assessing the ability of services to meet the needs of the child it will be important for them to consider these main themes from the literature in this field.

## **Methodology**

In reviewing the literature a number of sources were used and studies were selected from a search of relevant on-line databases including CINAHL, MEDLINE and paedpallit (ACT website). Initially only UK literature published after 1995 was selected although earlier seminal papers were incorporated into the discussion when it became clear that they were influential in the development of the current knowledge base in this field. Although this was not an exhaustive search it was notable that several key themes were recurrent within the literature. Recent guidance documents, surveys and publications from key organisations provided much valuable evidence of the current context of practice and the children and families’ experiences.

## **The child’s experience**

Due to the wide range of conditions which could be defined as life limiting, insight into the child’s experiences can be gained from existing literature in the fields of disability, technology dependence, palliative care and chronic illness.

This literature highlights the differences between the parents' and professionals' perceptions (often of problems and barriers), and the children's view of themselves, which focuses more on the things they value and want to be involved in. The issues raised by children are often the same, irrespective of ability – such as relationships, being able to communicate, feeling normal, access to activities, being comfortable, being respected and development of independence (Rabiee et al 2005; Murray 2002; Stone 2001). It is evident that children with life limiting conditions struggle to participate in activities which would place them in an environment where such opportunities would occur naturally. Specific research into the experience of children who have a non-malignant life threatening illness (Lenton et al 2001) identified that within the sample (n123) 60% have pain and discomfort, 35% are unable to walk and 25% have severe cognitive impairment. The resulting physical and behavioural difficulties will further compromise their ability to take advantage of leisure and recreational facilities.

A national survey (Shelley 2002) highlighted some of the issues related to accessing leisure facilities that were often experienced by these children. Contributory factors to these were provision and access to suitable facilities (e.g. toilets) but also staff awareness and attitudes. Children who have been consulted about the quality of services available to them consider the importance of staff attitude and approach, relationships, community links and personal development as being important. (Mitchell and Sloper 2001).

Lack of access to everyday leisure activities may inhibit their potential to relate to other children, and also to take the risks necessary for both their psychosocial and physical development (Langerman and Worrall 2005). The need to be accompanied was also recognised by children as an impediment to the peer interactions so necessary and valuable to them (Murray 2002).

For children whose condition would not allow for trips out of home the need for play, social interaction and stimulation remains necessary for fun and quality of life as well as for their development.

There is an increased likelihood that children with disability will be in a single parent family and an increased chance that they are living in poverty (Langerman and Worrall 2005). A higher than normal percentage of their mothers will not work, often due to their care responsibilities, rather than from personal choice (Kirk 1998). Such circumstances may affect the child's standard of living and access to opportunities.

A study by Lenton et al (2000) found that 54% of mothers and 34% of fathers of children with a (non malignant) life threatening illness had a mental health problem. In addition, they noted that 24% of the healthy siblings in these families had significant emotional and behavioural problems. It is likely that the child will be adversely affected by living within a family with such problems.

Although there is a wealth of literature on the experiences of families who have a child with a life limiting condition or disability, there is an acknowledged lack of information that considers the child's perspective. Whilst the importance of consulting with children

as users of NHS services has been recognised (Department of Health 1999, 2000, 2001, and Bristol Royal Infirmary Inquiry 2001) experience and knowledge of how this can be achieved practically is only recently emerging. Several writers (Balen et al 2000/2001; Mitchell and Sloper 2001 and Swallow and Macfadyen 2004) have highlighted the need to adopt age-appropriate, child-led communication strategies when consulting or researching children's views. However, operationalising these strategies is not without difficulties and is particularly challenging when working with children with communication problems (Rabiee et al 2005; Edmond and Eaton 2004).

## Needs

Children with life threatening/limiting conditions require both care and support from the time of diagnosis to their death. Dependent on the nature of the underlying clinical condition these needs will change as the child grows and develops but nonetheless they will be present throughout their lives. The needs of these children can vary greatly with some children being "technology dependent" (Wagner et al (1988) cited in Kirk 1998) whilst others may be intellectually impaired or have diminished, delayed or absent self-care skills.

Wagner et al (1988 in Kirk 1998) used the term "technology dependent" to describe children who required the use of medical equipment to support their body functions, in addition to nursing care to prevent death or disability. To meet the needs of such a child at home, carers have to acquire new clinical and technical skills, which ordinarily would be considered to be within the domain of the health care professionals. Townsley and Robinson (1999) commented on this necessity for parents to attain such skills by noting that few if any respite carers or services could offer a similar level of skill.

Whilst some children may be technology dependent other children have needs, which Beresford (1995 in Kirk 1998) referred to as "special care" needs. He determined these needs to require the carers

*" to go beyond the bounds of ordinary parenting"* (Beresford p9).

Similarly, Roberts and Lawton (2001) recognised that whilst all parents have to provide physical care for babies and young children this is expected to diminish with time. However, for parents of children with life threatening/limiting conditions these care needs persist or even increase with time.

The care needs of this group of children and young people may involve extra care with daily living activities, such as feeding, washing, toileting, mobility and dressing. For others there will be reliance on a range of equipment to support their needs for example, ventilators, suction machines and infusion pumps. Equally a large amount of consumable items may be used e.g. gastrostomy tubes, syringes, suction catheters and drug products (Kirk 1998). Olsen et al (2001) noted that children were being cared for in the home who needed oxygen therapy, naso-gastric feeding, central line care, intravenous medicines and anti-convulsant treatments.

Whilst the “technically dependent” child or the child requiring “special care” may involve parents in development of technical/clinical skills and knowledge, those children with behaviour problems pose quite different but equally demanding challenges. Such problems can include inconsolable crying, self harm, destructive and attention seeking behaviour. Parents can find themselves constantly having to keep their child occupied whilst also managing their pain, fits and medical crises (Roberts and Lawton 2001). Many parents describe the constant vigilance that is required to keep their child safe when they suffer with epileptic fits and choking episodes. It is not, therefore, surprising that parents report sleep disruption as such care is required “round the clock” (Roberts and Lawton 2001).

In addition to specific needs associated with the child’s underlying condition, the developmental needs of the child require attention to ensure that the child reaches their full potential. At times, maintaining the child’s physical health and safety may over ride concerns about stimulation to achieve developmental milestones. Providing opportunities for normalisation, play, and a change of environment can be challenging, given the amount of equipment required by some children, or disabled access for others (Langerman and Worrall 2005). Additional resources and personnel can make such activities achievable.

***The services funded by the successful NOF/BLF bid aimed to provide a flexible respite care scheme to meet the needs of children in a variety of settings by employing child health care workers. Children’s Community Nurses working with parents, devised individual programmes of care and child care workers were trained, supervised and supported to implement the care required.***

### **Impact on family**

The impact of having a child who has a life limiting condition affects the whole family at a number of different levels. The difficulties reported by families include physical, psychological, social, emotional and financial issues.

Physically they may be involved in a number of different (often lengthy) therapies and complex basic care (Joy 2005; Fisher 2001). Sleeping patterns can disrupt family life, and too little sleep or rest can affect parental capacity (Brinchman 1999).

Psychologically, the way that families perceive their child’s illness profoundly shapes their definition of adversity (Gravelle 1997). A perceived lack of control and constant uncertainty can change their perception of their lives, and this can be compounded by lack of real partnership in care delivery (Fisher 2001). Parents have identified an “overwhelming desire for information”(p 604), and have acknowledged the challenges in making the psychological adaptations necessitated by their child's changing condition while trying to maintain normal parenting tasks (Fisher 2001). Significant mental health problems may occur in both mothers and fathers (Joy, 2005; Lenton et al, 2001).

Socially, there can be a detrimental effect on family relationships, both marital and with other children (Kirk 1998). Parents have described the experience of caring for a disabled child as "lonely and difficult" (Haylock 1993), where "the house can seem like a prison, from which it is impossible to escape" (Brinchman 1999, p137).

Emotionally, family functioning and coping can be fragile and minor events can have a major impact on stress levels (Fisher 2001; Kirk 1998). Behavioural changes in siblings have been observed in such situations (Lenton et al 2001; Kirk 1998).

Financial problems can be a major contributor to family stress levels, particularly if the mother has had to leave employment. The cost of raising a disabled child is much greater than for a non-disabled child (Langerman and Worrall 2005; Wooley 1994; Dobson and Middleton 1998). An increase in electricity and water usage, the expense of travel and telephone calls (which may be long distance), trips to hospital, heating, clothing, bedding, laundry and equipment all contribute to the cost of caring for their child at home (Langerman and Worrall 2005; Kirk 1998). Families with a disabled child have a greater likelihood of living in poverty and debt (Langerman and Worrall 2005). Limited finances often mean that opportunities for leisure and family outings are restricted (Shelley 2002).

***In providing individualised care which was tailored to the child, the new NOF/BLF services aimed to deliver a flexible and sensitive service to the child. It was envisaged that parents' confidence levels with the service would increase to the point where they felt that their children were in "good hands".***

### **Critical times**

Depending on the child's condition their independence and abilities may change over time and this can be a slow deterioration or be precipitated by acute episodes of illness. This can lead to distress and frustration and affect their psychological and emotional well-being (Joy 2005). These children and their families suffer an uphill struggle typical of many degenerative conditions and this struggle can continue throughout their lives. Progression in the child's condition requires adjustment to changing physical needs and acceptance of the changes in the child's capacity (Gravelle 1997). The effectiveness of parental adaptation in these situations is recognised as having a major influence on the children and their wellbeing (Hentinen and Kyngas 1998).

Normal life events within the family (change in employment, moving house, pregnancy, starting school) may be particularly challenging as these children and their families often have to structure their lives around a rigid timetable to accommodate the child's needs (Redmond and Richardson 2003; Olsen and Maslin-Prothero 2001).

Whilst the impact on the family of caring for a child with a life limiting condition within the home is on-going, changes in the child's abilities e.g. illness, progression of condition, may precipitate periods of family disequilibrium. Whilst for other children developmental changes and physical growth are cause for celebration, for these families, they can signal increasing challenges for future care (Joy 2005).

**The NOF/BLF services aimed to offer a service to individual families which was flexible enough to take account of the changing requirements of the child's circumstances. The continuity of care provided by the home care workers and the relationship with the child and families aimed to facilitate timely recognition of need and appropriate referral to other support services such as counselling, family therapy and physical therapists.**

### **Burden of care**

Gravelle (1997) reflects that

*“Children with complex medical needs require an extraordinary quantity and quality of care which demands careful orchestration and which places enormous demands on parents”* (p738).

Whilst reviewing the literature in this area it is apparent that parents want recognition by professionals of their efforts in caring for their child (Roberts and Lawton 2001). Equally important to parents is the need to be regarded as partners in their child's care and this desire is closely linked with their need to retain control in order to minimise uncertainty (Fisher 2001).

Reed ((2000) in Redmond and Richardson 2003) suggests that there needs to be a shift in the professionals' perspective, from regarding the children as a problem and the mothers as “tragedy stricken”, to an engagement with families, which focuses upon normalisation.

It appears that whilst the need for extra care may be common to most disabled children, each child's and family's needs are unique. The importance of considering the impact of extra care needs across all areas of the family's daily life and family circumstances cannot be overlooked. According to Roberts and Lawton (2001) it is crucial that there is an assessment of the extra care needs, specific to the family circumstances for a true appreciation of the parent's work and to be able to obtain the services required.

Such unrelenting daily demands on parents and the continued “losses” and anticipation of progressive loss of function/abilities in their child leaves many emotionally and physically exhausted (Gravelle 1997).

In addition to the care needs of the individual child parents are also juggling the demands of the rest of the family, which may be other children, partners or elderly relatives. In assessing the needs of the child and family all of these factors would need to be taken into account if appropriate care is to be offered. Some families have reported that whilst day care (outside of the home) may be offered as a solution or support to the family it may equally prove to be an additional burden for the parents. Some parents report that the extra work involved in having to get the child ready to go out to day care often negates the benefits. (McNally et al 1999).

Redmond and Richardson (2003) reported that parents had reduced social lives with many mothers feeling obliged to give up work to act as the prime carer. There was also acknowledgement that parents constructed rigid timetables to cope with the diverse demands, these demands ranged from washing, dressing, feeding, lifting, housework to “quasi nursing” (Redmond and Richardson 2003; Kirk 1998). Difficulties were experienced in finding short term carers who parents felt they could trust to care for the child. Trips and family activities out of the house (considered as treats for other families) could be more stressful than enjoyable due to practical access difficulties and the complexity of the child’s condition or behavioural problems (Langerman and Worrall 2005).

Families suffered increased financial burden due to the costs of special clothing, equipment, transport or dietary needs which was made worse by the primary carer often not being in paid work (Langerman and Worrall 2005). Whilst all mothers wanted to be the main carer they found themselves having to fight, struggle and beg for appropriate resources and services. If they needed to go anywhere themselves, then careful adjustments had to be made to the daily schedule. Parents also commented that the constant need to advocate for their child was both stressful and time consuming. The continual threat of service withdrawal was an added stress to the families (Redmond and Richardson 2003).

**The NOF/BLF service aimed to support families and to share the burden of care – as defined by each individual family. This encompassed not only physical care, but hoped to facilitate stimulation and normalisation for the children.**

### **Gaps and pressures**

Lenton et al (2001) undertook a prevalence study of non malignant, life threatening illness in childhood, and noted that there had been a 400% underestimation of prevalence in previous reports. Possible reasons for this were a lack of clarity regarding definition, and the diversity of conditions, with no common source of medical care. In reviewing the literature on the services which were available, it is clear that service provision often varies both in organisation and quality, but has not grown in proportion to the developing needs in this area (Lenton et al 2001). Equipment and treatment that children require are not available when they need it (Langerman and Worrall 2005), resulting in further stress to families (Roberts and Lawton 2001; Beresford 1995 in Kirk 1998). A number of particular issues emerge from the literature. These include the need for effective co-ordination of services - which can be provided by a variety of agencies. Lack of this can lead to fragmented and duplicated services (Redmond and Richardson 2003 ; Kirk 1998; Haylock 1993). The waiting time to access services can be an issue (Audit Commission 2003; Redmond and Richardson 2003), and can be exacerbated by lengthy funding negotiations or confusing eligibility criteria (Audit Commission 2003; Kirk 1998).

The suitability of services can be problematic, in terms of timing (particularly difficult at night and weekends) and compatibility with family life - resulting in families having to organise routines around staff availability (Audit Commission 2003; Kirk 1998). The competency of carers, and their insight into the experiences of families was also highlighted as influencing the quality of the service received (Kirk 1998).

In recognising the importance of the families having trust in the carers, the NOF/BLF service aimed to develop this confidence by staff training and supervision, and the continuity of the relationships with the family's care worker. It was envisaged that the amount of time these workers could spend with the families would give a deeper insight into the family's experiences. The potential benefits of the NOF/BLF workers being part of an existing service (community children's nursing team) were that the additional care would enhance rather than duplicate, and be seamless rather than fragmented.

### **Effective care interventions**

Joy (2005) highlighted that the children themselves should feel comfortable with support provided for the family in caring for them. Children who have been consulted about what constitutes a quality service identified the importance of real choice making opportunities and the opportunity to participate in age appropriate community based leisure activities (Mitchell and Sloper 2001).

There were a number of factors that exemplified what families perceived as quality care. These included individualised care in which the family was involved in the planning and delivery (Law et al 2003; Dunst and Trivet 1996; Baine et al 1995). The continuity and consistency of care was also perceived as important, both in terms of care delivery and provision of equipment and supplies (Kirk 1999; Baine et al 1995). The nature of the care-givers focused on both technical and interpersonal factors (Law et al 2003; Dunst and Trivet, 1996). Accessibility and availability of service provision, and the environment in which it was delivered were also highlighted (Law et al 2003; Shelley 2002; Baine 1995). Satisfaction was improved if children and parents felt that staff were both respectful and supportive (Shelley 2002; King et al 2001).

The result of increased parental satisfaction with services was an increased compliance to treatment and a decrease in parental stress (Law et al 2003).

***The NOF/BLF service aimed to involve families in the planning of appropriate care, which could be delivered at the best time for the family. The workers were trained in the care and treatment required by each child with continuity of carers as part of the service design.***

Evaluation of the service was an integral part of the bid for NOF/BLF funding. A variety of strategies was planned in order to ascertain the views of children, parents and key health care professionals.

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